

**DOCTORAL THESIS IN COUNSELLING PSYCHOLOGY**

**THE LIVED EXPERIENCES OF BLACK AFRICAN HIV POSITIVE  
FATHERS IN THE UK**

Written by

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Thesis submitted in partial fulfilment of the requirements of the University of  
Wolverhampton for the post-graduate award of:

**Practitioner Doctorate in Counselling Psychology  
D. Couns. Psych.**

The following research has been conducted in line with the guidelines presented for  
the module: Doctoral Portfolio, PS5018.

March 2016



## **Declaration**

The research dossier of any part thereof has not previously been presented in any form to the University or to any other body whether for the purposes of assessment, publication or for any other purpose (unless otherwise indicated). With the exception of any express acknowledgments, references and/or bibliographies cited in the work, I confirm that the intellectual content of the work is the result of my own efforts and of no other person, beyond the role expected of my research supervisors Dr Victoria Galbraith and Dr Niall Galbraith.

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## **Acknowledgements**

I would like to thank my friends and family who have been by my side throughout this doctorate programme. Without your endless support, guidance and encouragement this would not have been possible.

During my academic studies, I have come across some remarkable and passionate lecturers. Thank you for sharing your knowledge and enthusiasm for Counselling Psychology with me.

Last but by far not the least, I would like to thank all the staff, supervisors, clients and service users that I have met and had the privilege of working with in my clinical placements and throughout the research process, you have been my most valuable and inspirational teachers during these three years.

## **Abstract**

**Background:** HIV has been reconceptualised as a long term chronic health condition due to advances in highly active antiretroviral therapy. Nonetheless it remains a stigmatising and under-recognised condition. One social group that HIV disproportionately affects is the Black African population. However there is a dearth of research into the lived experiences of HIV positive Black African communities in the U.K. specific to parenting.

**Objectives:** This study seeks to explore the lived experience of Black African HIV positive fathers, living in the UK. This is of significance to counselling psychologists because illness representation models typically neglect the interactions of significant others and wider social contexts when conceptualising the impact of illness.

**Design:** This research utilises a qualitative method, Interpretative Phenomenological Analysis (IPA) to examine data. IPA is effectual in new and complex areas of study, concerning identity and meaning making. It enables the researcher to acquire an 'insider perspective' into people's cognitive reasoning as well as the social and cultural context surrounding experiences.

**Method:** Six Black African HIV positive fathers were recruited via HIV charities. Participants were requested to attend a 60-90 minute, semi-structured interview and asked questions about their experiences of living with HIV and how it impacts on their role as fathers.

**Results:** Four super-ordinate themes were identified: 1) Responses to HIV diagnosis-the demise of the physical and social self 2) HIV stigma-'they don't realise that anyone can get it' 3) Re-emergence of the self 4) Fatherhood- a changing identity.

The results revealed experiences of living with HIV and the impact that this has on their role as fathers. Participants talked about their initial reactions and responses to receiving a diagnosis of HIV, as well as the challenges of living with HIV within their communities and wider society that impacted on their disclosure decisions. The

research highlights the significance of HIV support services that helped participants to accept their HIV status. The participants wished to play a key role in the lives of their children. The findings of this study emphasise the importance of incorporating interventions that help black African men to view themselves in a positive light and to foster their parenting role following a diagnosis of HIV. The results of the analysis are considered in light of existing theory and their clinical implications.

**Key words:** HIV, Fatherhood, Fathers, African, Masculinity, Men, United Kingdom.

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## INTRODUCTION

HIV remains one of the world's most significant public health challenges particularly in low to middle income countries (World Health Organisation, 2015) disproportionately affecting men who have sex with men (MSM) and black African heterosexual communities. Black Africans are the second largest group to be affected by HIV. Although the condition is no longer life limiting, due to advances in medical treatment, HIV continues to carry a number of disease related stressors that impact on individuals, families and wider communities. Consequently research carried out in this area has largely focussed on the quality of life factors that impact on people living with HIV (PLHIV), exploring behaviour, risk and biomedical aspects of the disease (Treisman, 2011).

In psychology research, a small number of qualitative studies have focused on the lived experiences of HIV positive black Africans in the United Kingdom. These have captured the issues of self-identity and the embodied experience of an HIV diagnosis in relation to black African communities. These studies uncovered the impact of stigma, social isolation and inequalities that can affect people living with HIV as well as the adjustment, positive coping mechanisms and resilience of this population (Tait, 2013; Dibbs & Kamlesh, 2011; Treisman, Jones & Shaw, 2013; Flowers, Davis, Hart, Rosengarten, Frankis & Imrie, 2006). The majority of studies have been of black African women (Tait, 2013; Treisman, Jones & Shaw, 2013 & Dibbs & Kamlesh, 2012) and one study used a mixed sample of men and women (Flowers, et al 2006). A study by Doyal, Anderson & Paparini (2009) focussed on the narratives of heterosexual black African men and their changing masculine identities, following an HIV diagnosis. This study explored fatherhood in the wider context of masculinity and most participants expressed a desire to have children.

In relation to parenting and HIV, studies have also focussed on issues of HIV disclosure (see Qiao, Li & Stanton, 2013). Treisman, Jones and Shaw's (2013) study explored the impact on black African Women's identity of finding out about their HIV status during pregnancy and draws out the issue of women's concerns about passing the virus on to their children and issues of breastfeeding, particularly as this plays a significant role in motherhood culturally.

Studies have not exclusively explored the impact of a HIV diagnosis for black African men, particularly in the context of fatherhood. Consequently little is known about their unique experiences of living with HIV and how this may impact on their role as fathers.

This investigation is important to counselling psychology because counselling psychologists endeavour to gain knowledge about diverse experiences and to challenge inequalities and pathologising concepts that are derived from discrimination. In the field of HIV, counselling psychology input is significant at all levels of therapeutic interventions to promote the health and well-being of individuals living with HIV (Werth, Borges, McNally, Maguire & Britton, 2008). This study utilises Interpretative Phenomenological Analysis (IPA) because it is considered to be suitable in allowing for an in depth analysis of a small sample, paying attention to the unique variation of experiences, interpersonal issues, meaning, context and culture. This is particularly appropriate for under-researched groups, as IPA allows for unexpected findings to emerge (Barker, Pistrang & Elliott, 2002).

The research question is therefore, '*what are the lived experiences of black African HIV positive fathers in the UK?*'

## CHAPTER 1

### LITERATURE REVIEW

For this literature review the following E-journals and electronic databases were searched from inception to January 2016. These were PsychINFO, Web of Science, Sage Journals online, Wiley Interscience, Chrochane Database. A combination of online and offline search procedures took place, including checking references of retrieved studies and books, internet searches and unpublished theses. Studies considered to have the most relevant information on men and fathers living with HIV were included in the literature review. Non- English language studies were excluded.

The following search terms were used:

HIV, diagnosis of HIV, personal experience, prevalence, adjustment, counselling, psychology

*With men/fatherhood/care-giving with black African, African origin*

This literature review is not exhaustive and aims to inform the reader about the conceptual, contextual and cultural issues, relevant to black Africans living with HIV. Sections one and two, presents background information about migration, prevalence rates of HIV, routes of transmission and diagnoses in black African adults as well as commonly experienced mental health challenges, in relation to HIV. The third part of the review explores the social issue of HIV stigma and how this is perpetuated and reinforced within smaller communities and wider society. In the fourth section, the concept of masculinity is considered in relation to cultural expectations and practices, particularly the impact on men's identities and their role as fathers in Africa. Here, the concept of hegemonic masculinity is critically reviewed in light of HIV. Although limited, existing research into the impact of migration on father-child relationships is considered in section five. Often parents are presented with a dilemma about when and how to disclose their HIV status to children. Here this is considered in relation to the disease progression and competing consequences models of disclosure, in section six.

Section seven explores adjustment to a HIV diagnosis, taking into account the positive changes that people can experience, that has been documented in research

into post-traumatic growth and the crucial role that religion and spirituality can play in this. Finally the rationale for this current study is presented in section eight, as well as its relevance to counselling psychology. Finally section nine details the rationale for the study and research question.

### **1.1 Migration from Africa.**

Migration from African countries to the UK increased during the 1990's and early 2000's mainly due to the political and civil unrest in Africa. Africans were forced to leave their homeland, arriving in the UK to seek asylum or refuge (Crawley, 2010). Forced migration means having to adapt to a different culture and a way of living, with many facing an uncertain future in the UK (Dodds, 2006). Due to their uncertain immigration status many migrants have been unable to work or access benefits in the UK. A lack of rights and access to health and social care has meant that most live in poverty despite having gained a good level of education prior to their arrival in the UK (Dodds, 2006). Some may have arrived in the UK leaving their families, including their children and partners, behind (Dodds, 2006).

### **1.2 HIV prevalence in the UK.**

In the UK there are currently estimated to be 103,700 people living with HIV, approximately 18,100 people are unaware that they are infected and in 2014, 6,151 people were diagnosed with HIV. Black African men and women make up 29% of the overall population living with HIV in the UK (NAT, 2015) and approximately 85% of African residents were infected prior to leaving their country of origin in 2006. In 2009, 25% had acquired HIV in the UK. Over time, the rates of infection in the UK have increased (Public Health England, 2013). However statistics use broad ethnic categories and fail to distinguish between nationalities, which potentially results in conservative estimates (DeCock & Low, 2007).

#### **1.2.1 HIV transmission.**

HIV is commonly passed on by having unprotected sex and sharing infected injecting equipment, including needles. It can be transmitted from mother to child during pregnancy, birth and breast-feeding. The virus attacks the immune system, specifically white blood cells named CD4 cells, weakening its ability to fight infections and disease. Currently there is no cure for HIV. Advances in treatment, namely

Highly Active Anti-retroviral Treatment (HAART) means that the disease can be controlled and managed therefore increasing life expectancy (Avert, 2015). However if HIV remains untreated, it can progress to AIDS. This occurs when the body is no longer able to fight off life-threatening infections. In developed countries where there is access to treatment for HIV, it is rare for this disease to progress to AIDS. Therefore it has been reclassified as a chronic long term health condition (Pakenham, Dadda & Terry, 1996).

### **1.2.2 HIV diagnoses in black African adults.**

African adults residing in the UK often present with a different clinical spectrum of HIV/AIDS to non-Africans (NICE, 2011). Co-infection with tuberculosis and late presentation to HIV services often at the onset of symptoms from AIDS related illnesses are frequent (Johnson, Carey, Chaudoir, & Reid, 2006). Thus African adults often discover their status at a more advanced stage of disease progression and with lower CD4 counts at diagnosis (Rice, Delpech, Sadler, Yin, & Elford, 2013, Burns, Fakoya, Copas, & French, 2001; Low, Paine, Clark, Mahalingham, & Pozniak, 1996; Malanda, Meadows, & Catalan, 2001). In 2014, 40% of adults newly diagnosed with HIV, were diagnosed after they should have started treatment (NAT, 2015), however the percentage of black African people is unknown here.

A number of reasons have been found for low levels of testing, such as lower perceived risk of infection, lack of information regarding available services and socio-economic and legal barriers to accessing services (Medical Research Council, 2004). In 2011 the National Institute of Clinical Excellence (NICE) recommended that HIV testing should be made readily available in community settings, such as health settings. This was found to be operationally viable, however no significant association was found between ethnicity and test uptake rates. Therefore, it is unclear whether black African communities are actually benefitting from this provision.

Of more specific relevance to HIV services, black African men's needs are often overlooked as there is a tendency for HIV services to be orientated towards meeting the needs of women and children. Thus men can find support structures, such as clinics, inaccessible which contribute to men being less likely than women to be

tested for HIV (Barker & Ricardo, 2005). This is particularly problematic, given that men generally are less likely than women to seek help for health-related concerns and access support (Pearson & Makadzange, 2008). Therefore their physical health can be compromised as well as their mental health.

### **1.2.3 HIV and mental health.**

Having a diagnosis of HIV can impact on a person's ability to cope (Basavaraj, Navya & Rashmi, 2010). Anxiety and depression have been closely linked to HIV (BHIVA, 2011). For example, Weatherburn, Keogh, Reid, Dodds, Bourne et al, (2009) in their research has a sample of ( $n=1777$ ) participants that completed a survey. The mean age of men was ( $m=42$ ) for those completing questionnaire booklets and  $m=40$  for those completing an on-line survey. Participant were recruited from charitable organisations consisting of 137 heterosexual men and 327 heterosexual women, 1154 gay men and 60 bisexual men, 7 lesbian women, 3 gay women and 6 bisexual women. 1180 were White British, 258 African, 23 Asian and 41 had dual heritage. The research found that 72 per cent of people living with HIV had problems managing anxiety and depression. However, this research used self-report surveys to gather data, which may mean that mental health challenges were either under or over reported, raising questions about the reliability of those prevalence estimates. (Sigma Research Group, 2009).

Furthermore symptoms such as fatigue, pain and insomnia are associated with HIV as well as depression. These symptoms have been observed throughout the course of a person's HIV illness, even when depression is not present. Despite this, in both early and late phases of HIV disease, these symptoms correlate more closely with a mood disorder, than with clinical correlates of infection (Benton, Blume, & Dubé, 2010). Both chronic stress and harmful coping skills can also affect the immune system, further reducing the quality of physical and mental health (Segerstrom, & Miller 2004).

In addition, aspects of the immigration process can have a severe negative impact on mental health (Orton, Griffiths & Waterman 2012; Foster, 2001). Research has highlighted that refugees and asylum seekers are poorly served by mental health services whilst simultaneously being at greater risk from stress, anxiety and

depression (Sen, Exworthy, & Forrester, 2014). Black African men are also more likely than men from other ethnic backgrounds to be screened for Post Traumatic Stress Disorder (PTSD) (Ruiz & Bhugra, 2010). Research across different countries and situations has consistently found that there is an increased prevalence of PTSD, depression and anxiety as well as co-morbid disorders, in those with physical health problems. However, the interpretation of problems can be over simplified, from a lack of awareness of the impact of trauma, to over attributing all mental health presentations to past experiences. In fact a range of factors interplay, such as war conflict, natural disasters, family loss, different types of violence, abuse, sexual exploitation and brain changes. These have a cumulative effect but are also mediated by post-immigration stressors of socioeconomic adversity, adjustment to a new society and isolation (Vostanis, 2014). These factors need to be taken into consideration when delivering therapeutic interventions to meet the needs of this population.

#### **1.2.4 Summary.**

Migration from African countries can occur due to political and civil unrest. Many are forced to leave their homeland and arrive in the UK seeking asylum or refuge. Refugees and asylum seekers may find themselves living in poverty because their uncertain immigration status does not permit them to seek work. They may have limited entitlement to benefits, resulting in economic adversity. In addition heterosexual black African men and women are the second largest group to be affected by HIV and they typically present with a different disease spectrum to non-Africans. They often access HIV treatment and services with the onset of symptoms of AIDS, discovering their HIV statuses at a more advanced state of disease progression. Some explanations for this are: low perceived risk of infection, lack of information about available services, socio-economic impediments and legal barriers to accessing services. Although national guidelines suggest making HIV testing more readily accessible in community health settings, research has yet to be undertaken on the development, provision, uptake and effectiveness of such services. Aside from the medical aspects of the disease, people living with HIV often experience mental health challenges including post-traumatic stress disorder. This can be compounded by the immigration process, which can be inherently stressful. Flexible services and therapeutic models need to be applied to real settings that are adjusted



to meet cultural needs and are integrated with existing services (Vostanis, 2014). This is particularly important because a diagnosis of HIV can mean that black Africans find that they have to redefine their self-identities within a morass of variables, particularly as they hold a number of stigmatising identities.

### **1.3 HIV related stigma.**

Although there have been considerable efforts to raise awareness about HIV and its prevention, they have been greatly hindered by the fact that HIV is a heavily stigmatising condition (Parker & Aggleton, 2003). Goffman (1963) described stigma as a situation in which individual and/or groups of people are ineligible for full social acceptance. This occurs when physical attributes, character traits or behaviours are perceived as disordered or contra-normative and where differences are labelled and made salient rather than overlooked (Miller, Read, Francisco, Ellen, 2012). Stigma is therefore enduring and negatively viewed by society; it is discernible from two related concepts, prejudice and discrimination (Herek, 2002).

Prejudice is an unhelpful attitude reflecting evaluation or judgement that resides in the minds of individuals. Stigma in contrast, exists in the structure and relations of society. Stigma can therefore be a manifestation of prejudice when it reflects society's negative judgement of a target group. Discrimination, in contrast, is behavioural, referring to the differential treatment of individuals according to their membership of a particular group. Discrimination is the act, prejudice is the attitude. Attitudes often find expression in individual recurring behaviour and in this way individuals can discriminate against members of any group. However, only when behaviour is condoned or encouraged at a societal level, does it become stigma (Herek, 2002).

Much of the empirical research that has been undertaken on stigma related to HIV and AIDS has focussed heavily on the beliefs and attitudes of those who are perceived to have stigmatised others. Studies have investigated the emotional responses of the target population groups and attempted to break down misconceptions about routes of transmission (Parker & Aggleton, 2003). Whilst this may be helpful in increasing empathy and reducing fear, the concept of stigma itself, remains as an individual act where people choose to stigmatise others instead of understanding it in relation to broader notions of power and control (Parker &

Aggleton, 2003). For example, HIV is associated with destabilising the moral fibre of society because of a widely held and socially accepted belief that people living with HIV (PLHIV) are culpable, through engagement in socially unacceptable behaviour (Herek, 2002). PLHIV are therefore subject to varying degrees of personal rejection, social ostracism and discrimination (Herek, 2002), created by enacted stigma (Scrambler, 2010).

Stigma is therefore a social process that can only be understood in the context of wider notions of inequality, power and domination (Gilmore & Somerville, 1994). Stigma is positioned to legitimise a dominant status within existing structures of social inequality (see Foucault 1977, 1978). The concept of stigma is far from abstract; it is part of the complex power struggles that are at the centre of social life. Stigma is reinforced by poverty, gender inequalities and global capitalism that shape the context within which the HIV epidemic flourishes at a universal level. Individual cognitive processes, instincts and sense of personal vulnerability impact on social processes at a micro level (Parker & Aggleton, 2003).

Dodds, Keogh, Chime, Haruperi, Nabulya, & Ssanyu Sseruma, (2004) conducted focus group research with Black African heterosexual men and women as well as gay and bisexual men, both British and non-British in the UK. This study consisted of 124 participants and 20 focus groups were conducted. Of those participants that completed a demographic form, 41 were African women, 44 were black African men and 34 identified themselves as being gay or bi-sexual. The mean age of gay and bisexual men was 35; the mean age of African women was 40 and 39 for black African men. The research explored the ways in which stigma impacted on these social groups living with HIV. Although focus group findings cannot be generalised, and some of the more subtle differences within and between the groups may not have been identified (Kruger, 1994) here, the study did find that Black African communities experience high levels of social, economic, political disadvantage and marginalisation as a result, often feeling threatened by the general public and fearing attack from government (Dodds, 2006). In order to gain some sense of belonging and identity, black African migrants developed 'Pan-African' communities, as a primary response to social and economic inequality. Although members were highly diverse, they shared some homogeneity holding shared history, culture and

experiences of discrimination in the UK (Bourne, Dodds, Weatherburn, Madyara, Ntyabera, et al (2011). These communities consisted of church goers, friends, family and people from similar cultural, tribal or national backgrounds. They provide support and basic necessities for members, helping them to foster safety during times of uncertainty, which in itself was mainly caused by the possibility of repatriation and isolation (Dodds, 2006). Nonetheless, divisions can also be prevalent between smaller sub-groups due to historical and cultural differences (Sigma Research Group, 2011).

### **1.3.1 Community level stigma.**

Additionally HIV is greatly stigmatised in the African communities (Goldin, 1994; Bhatt, 1996) and great care is taken not to disclose HIV statuses to those within the pan African community. Often, those who are stigmatised accept and internalise the stigma they are subject to, they feel an internal sense of shame, fear of persecution and anticipation of rejection. This has been termed by Scambler (2010) as 'felt stigma'. Here actual discrimination does not need to occur for stigmatised people to suffer as a result of their status. Felt stigma encourages individuals with stigmatised conditions to pass as members of non-stigmatised groups in society. However this is likely to increase personal psychological distress, feelings of vulnerability and isolation (Herek, 2002).

Dodds et al (2004) found community level stigma related to HIV was a major concern for most PLHIV, impacting on social support that people with HIV were willing and able to access from traditional sources such as friends and family. This meant keeping difficult family secrets, adding to pressure on relationships. Those experiencing rejection, lacked self-confidence resulting in isolation. This study was qualitative and utilised a small sample size, so the findings should be interpreted cautiously in the absence of additional research. Therefore PLHIV in the community withdrew from their support networks because of the potential for stigma related discrimination; instead they relied on support networks consisting of other Africans living with HIV (Dodds, 2006).

### **1.3.2 HIV stigma and discrimination in wider society.**

A survey conducted by the National AIDS Trust (NAT) found that participants often reported discriminatory attitudes from healthcare professionals, once their HIV status

became known. For example, dentists gave their HIV positive patients the last appointment of the day. Some nurses refused to enter hospital rooms of HIV positive patients. Elford, Ibrahim, Bukutu and Anderson, (2008), conducted a quantitative study consisting of people accessing HIV outpatient clinics in London hospitals. 1,385 participants responded to a questionnaire, relating to discrimination. The sample included 448 heterosexual women, 210 heterosexual men of black African origin, 727 gay/bisexual men, (621 white 106 ethnic minority). The research found that HIV discrimination was experienced by black Africans in the UK. Nearly one third of people living with HIV in London said they had been discriminated against because of their HIV status. Of those who had experienced HIV-related discrimination, almost half said that this had involved a health care worker including their dentist, GP (primary care physician) and hospital staff outside the HIV clinic. There was no statistical difference between gay men and black African people reporting discrimination. This study was based on self-reported data and relied in part on the respondents' interpretation of a negative experience being HIV related and their willingness to report their experience. As both gay men and black African groups hold two or more stigmatised identities, it may be difficult to differentiate between HIV related discrimination from discrimination related to other stigmatized identities (Elford, Ibrahim, Bukutu and Anderson, 2008). HIV becomes an additional burden, causing isolation and discrimination within Pan-African communities and wider social context (see also Flowers Davis Hart, Rosengarten & Imrie, 2006; Triesman, Jones & Shaw, 2013). The above research highlights how stigma can feed upon, strengthen and reproduce existing inequalities in society (Parker & Aggleton, 2003).

### **1.3.3 Summary.**

Black African men and women arriving in the UK are faced with a number of stressors, for example, arriving in a new country, after leaving friends and family behind. They may be forced to live in poor housing conditions, unable to work in many cases because of their uncertain immigration status and with little entitlement to rights and services; these factors all contributing towards social exclusion. Men may draw upon the support of people who have also arrived in the UK in a similar way and through this type of support network Pan-African communities are formed. Nonetheless, a diagnosis of HIV can pose as a threat to the stability of such

communities and can lead to isolation and psychological health challenges as well as unhelpful coping strategies. This is because HIV is a stigmatising condition, both within black African communities and wider society. Those with HIV are seen as a threat to the fabric of communities. Black men therefore may be less inclined to access treatment and support. Other factors associated with high prevalence rates of HIV among black African communities will now be considered below, emphasising the construction of masculinity for black African men.

#### **1.4 Masculinity and HIV.**

Masculinity is a concept that is socially and historically constructed, it is therefore fluid and dynamic (Morrell, 2001). Although the concept of masculinity is situated within diverse social contexts, there is one prevailing form: hegemonic masculinity (Connell & Messerschmidt 1995). Hegemonic masculinity suggests a number of characteristics that men are encouraged to internalise and which form the scripts for masculine behaviour. These characteristics include violence, aggression, stoicism, courage, toughness, risk-taking, adventure, thrill-seeking, competitiveness, achievement and success (Donaldson, 1993; Moynihan, 1998). In relation to health, dominant forms of masculinity have been shown to present problems with regard to help-seeking, where taboos on men seeking healthcare are present in many societies (Courtenay, 2000). Imposed characteristics of successful masculinity can propel men towards engaging in risky behaviours.

For black African men the HIV/AIDS epidemic led to a focus on masculinities within sexual health and reproductive health discourse and policies (Bujra, 2000, Gosine, 2004). In Africa and the UK, the main route of transmission is through heterosexual sex affected by gender imbalances. Men often determine the frequency and type of sexual encounters characterised by unprotected sex and multiple sexual partners. Although the transmission of the disease may not be deliberate, a lack of awareness, access to condoms and skills to negotiate safe sex can all play a part in the spread of HIV (Foreman, 1999).

##### **1.4.1 African masculine identity.**

In Africa, the ways in which dominant forms of masculinity interweave with men's identity has been documented by many writers (Morrell, 2001; Kometsi, 2004; Reid & Walker, 2005:). For example, Lynch, Brouard, & Visser, (2010) carried out focus

group discussions in South Africa with black African men and used discourse analysis to interpret the findings. They found that three discourses emerged, the first relating primarily to being an independent provider for themselves and the family. Historically, independence has been achieved through migrant work, enabling men to gain financial capital, used to set up a household, pay lobala (bridewealth) and start a family. Secondly, participants identified practices they regard as contributing to masculinity in terms of cultural expectations. From a young age, sexual prowess evidenced by multiple sexual partners forms a significant part of men's identities (Woods & Jewkes, 2001; Walker, Reid & Cornell, 2004; Lerclerc-Madlala, 2005; Mfecane, Struthers, Gray & McIntyre, 2005) and it is a mark of successful masculinity (Foreman, 1999). Terms such as udlalani (playboy) and Ingagara (admiration for achieving something) are used to positively refer to a man who has many partners amongst black Africans and men reported that they often feel the pressure to conform to such cultural norms surrounding hegemonic masculinity, placing men at risk of contracting HIV (Foreman, 1999). Furthermore, this may also discourage men from seeking help if they become ill and this could lead to denial of the risks (Lynch, Brouard & Visser, 2010). Men can be viewed as perpetrators of HIV (Caldwell, Caldwell, & Quiggin, 1989) and also vulnerable to HIV (Gupta, 2000). Furthermore, marginalising depictions of men in the context of HIV/AIDS can have harmful effects, placing men in categories of social deviance which could obstruct efforts to change behaviour (Jobson & Wyckoff-Wheeler, 2002). These factors may also contribute to late diagnosis of HIV amongst black African men (see section 1.2.2). In the final discourse, normative masculinity consisted of challenges to men after which a transformed masculinity emerged, where men living with HIV began to challenge restrictive masculinity and actively contradicted normative masculinity by seeking support in the first instance.

All men were accessing HIV support services at the times and the findings do not account for those men not engaged in services but who were living with HIV, who may well have reflected different constructions of masculinity. Additionally this study was undertaken in South Africa and its findings may not be generalisable to populations in other countries. It is unclear here what the process was that took place that enabled men to challenge the normative masculinity and seek support. Nevertheless the research does highlight the value of challenging masculinity

constructions within discourse, HIV services and wider communities in the UK. Ultimately, ideological constructions of masculinity also impact on and determine black African men's roles as fathers (Morrell 2006).

#### **1.4.2 Fatherhood.**

Fatherhood is a more complex notion, concerning parenting and contributing to the child's emotional and physical wellbeing (Engle & Lenard, 1995). Hegemonic constructions of masculinity relating to the biological fathering of children are a crucial symbol for male virility (Datta, 2007). Having children also contributes to men's natural biological progression into various roles such as father and grandfather (Townsend, 2001). Therefore fathers can make a valuable contribution to a child's development and adult development (Palkovitz, Copes, & Woolfolk, 2001; Roggman, Boyce, Cook, Christiansen & Jones, 2004). Erikson (1982), places importance on this stipulating that individuals successfully resolve crises and struggles that are distinctly social in nature, during the life span. These involve establishing a sense of trust in others, developing a perception of identity in society and helping the next generation prepare for the future. According to Erikson, middle adulthood is characterized as a time when people offset their fears of stagnation (polarity) with expressions of generativity (polarity); this includes participation in wider society, caring for family and being economically active. Thus this period is defined heavily by the roles people play within family and community structures (Sugarman, 2000). Erikson believed that men's involvement in the care of children is an important step in their personal growth (Daly, 1995; Snarey, 1993) and African social norms also advocate parenthood as an ultimate path to personal fulfillment. However Erikson's stage dependent theory can be criticized for being deterministic and reductionist and although Erikson does acknowledge that one polarity outweighs the other, this process still appears static and linear (Sugarman, 2004). For example, parenting roles are determined by gender organization, social and economic structures. Nurturing and caring responsibilities mainly fall on mothers and fathers are valued for providing basic needs, disciplining and passing skills onto children (Datta, 2007). Such parameters can enhance or restrict the level of parenting responsibility and involvement of fathers concerning the welfare of their children.

### **1.4.3 Fatherhood in Africa.**

Gendered differences in the construction and practices of parenting have created stereotypical notions of deviant fathers in Africa. These constructs are bound up within the concept of fatherhood and veil significant differences in practices of fatherhood (Chopra, 2001). Research has highlighted uniform images of isolated, unsupported mothers, with women's lives distinguished primarily in terms of motherhood, whilst men's lives have been characterized without reference to fatherhood. This could be because of insufficient economic resources which means that men have to work away from home; or the lack of policies promoting father attachment (Engle & Leonard, 1995).

Ritcher, Chikovore & Makusha, (2010) conducted in depth interviews with thirteen biological fathers and eight biological mothers in KwaZulu Natal, South Africa. Participants were either married, co-habiting, unmarried or non-resident with their children's fathers. Using Grounded Theory, to analyze transcripts, the study found that mothers can be facilitators or can restrict the fathers' access to their children, particularly when they are unmarried and non-resident. In relation to the division of labour, culturally, women were seen to nurture and take care of the family, whilst the men's role to provide financially. This prevented some men from getting involved in the care of their children, even when they wished too. Cultural expectation of paying lobola (bridal wealth) created conditions of cultural gate-keeping and some men were unable to pay this. So women and children stayed with their families and controlled the fathers' access to their children.

This study highlights the impact of maternal and cultural gatekeeping on father involvement which ultimately impacts on the father-child relationship. One limitation of this study was that it did not interview unmarried, non-resident fathers who were separated from their children. This may have yielded different findings in relation to factors that impact on fathers and their involvement with their children. Additionally, it was a small scale study and the findings may not be generalisable to father-mother dyad accounts.

### **1.4.4 Fatherhood in the context of HIV in Africa.**

The devastating consequences of HIV/AIDS on the ability of fathers to fulfill the expected paternal obligations were sensitively explored in a qualitative study in Cape



Town by Coetzee & Swartz (2004). Many of the participants in this study had children who were also HIV positive. Fathers emphasized the severe lack of resources as making it hard to live. The needs of the sick child had to be weighed against the father's need to rest, work and earn money. Anti-retroviral therapy was viewed here as essential in providing a platform to enable men to renew their engagement as fathers and to increase family cohesion. In contrast, regardless of the HIV epidemic, many fathers were found to be absent from their children and homes in a qualitative study conducted by Hunter (2004) specifically in South Africa, where HIV/AIDS had left many children orphaned or living with relatives, mainly grandparents and extended families. Here polygamy was common and frequently fathers were unknown to their children. These studies were small and qualitative and no distinctions were made between social class and economic backgrounds of families. These two factors have impacted greatly on the affects of HIV. The availability and accessibility of anti-retroviral medication may make a significant difference in the degree of family cohesion.

#### **1.4.5 Summary.**

Hegemonic masculinity is socially and culturally constructed. Men are encouraged to internalise scripts for masculine behaviour, however adopting these characteristics can hinder help-seeking behaviour and increase the risk of the spread of HIV. Dominant forms of masculinity also relate to, fathering children, being financially independent, and providing for the family. A combination of these factors has subsequently created stereotypical notions of deviant/absent fathers and economic instability, these factors when coupled with cultural expectations can make the father-child relationship distant and fragmented. The efforts of black men to be fathers need to be understood within the internal working models of their cultures. In light of political unrest and conflict, some have sought refuge in other countries; this can further impact on family ties (see section 1.1).

#### **1.5 Step-wise migration.**

The population of immigrant fathers is highly diverse and it is important to study immigrant fathers in the context of their family systems, community and cultures (Braver & Griffin, 2000). There is relatively little research on the impact of immigration upon the father-child relationship and existing research in this area has

typically focused on middle-class western populations (Marsiglio, Amato, Day, Lamb, 2000). Furthermore, little is known about the impact of step-wise immigration, (Hondagneu-Sotelo, 1992), whereby children may follow one or both parents to the host country at a later time. Immigration is a substantial transition for fathers and can represent a severe challenge to their family's wellbeing (Chuang & Morano, 2008).

### **1.5.1 The deficit perspective.**

Two perspectives have been developed to understand some of the challenges faced by immigrant fathers. The deficit perspective stresses the notion that immigration challenges the stability and continuity of fathers' roles, identity and well-being. This theoretical approach perceives immigration as a source of stress, and a risk factor for families and children (Bourgois, 1998, Dettlaff & Rycraft, 2006; Foster, 2001). Suárez-Orozco & Suárez-Orozco, (2009) carried out quantitative research to explore the impact of immigration in Boston and San Francisco. They recruited participants from fifty schools, and distributed structured questionnaires to immigrant parents and children. The study found that immigration is associated with psychological distress, anxiety and somatic symptoms (Berry, 1992). However first, second and third generation children and parents were included in this study, and were considered as a single group for purposes of analysis and therefore no distinctions or variations between these generations were revealed by this research. It is unclear whether those with refugee or asylum seeker status were included in the study. This could make a difference to findings given the additional stress of having uncertain immigration status.

Migrants have to cope with the practical challenges of day to day life in a host country where on-going change and adaptation affects all parts of their life (Kurman & Ronen, 2004). The acculturation process can cause cultural crisis, decline in health, emotional challenges and social difficulties (Lerner, Kertes, & Zilber, 2005). These risk factors are associated with under-going 'cultural shock'. Individuals have to adapt to new living arrangements, new home, social environment, language, culture, place of work and profession. Often social support and family systems are undermined. Unemployment or taking low paid work, is commonly experienced by immigrant fathers (Parke, Vega, Cookson, Perez-Brena & Coltrane, 2008), undermining fathers' perceptions of their status and success (Lamb & Bougher,

2009) as breadwinners and head of families. This may also impact on the way in which their wives and children perceive them. If fathers have asylum seeker or refugee status it may prevent them from gaining employment all together (see section 1.1).

Accordingly a father's physical, psychological health, self-image and ability to cope with stress and heightened anxiety levels may be challenged. Wives and children may integrate more readily into the host culture and this could present as a threat to the father's status and consequently family stability (Suárez-Orozco & Suárez-Orozco, 2009). Declines in self-esteem, due to unemployment, poverty and loss of social status have been linked to isolation, marginalisation, and increased alcohol intake as well as punishing and neglectful behaviour towards children.

If fathers have left their children behind they may experience sadness, grief and anxiety at this separation (Suárez-Orozco, Todorova, & Louie, 2002). Often when they are reunited, fathers frequently report difficulties in reasserting their authority (Arnold, 1997). Attachment difficulties have also been noted because children may withdraw from fathers when they are reunited (Wilkes, 1992). Conflict may also occur between children and their fathers if they discover that their children are dressing and behaving in accordance with the host society, the resulting cultural conflict further contributing to strained child-father relationships (Szapocznik & Kurtiries, 1993).

### **1.5.2 The generative resilience perspective.**

In contrast to the deficit perspective, the generative resilience perspective represents immigration as being positively related to family unity and children outcomes (Boyd, 2002). New immigrant families are thought to be strengthened by cultural means and social practices, transcended from their home countries as well as economic, cultural and social forces in the host country (Foner, 1997).

Roer-Stier, Stier, Este, Shimoni and Clark (2005) found that regardless of their cultural background, fathers stressed the new opportunities and resources available in the host country. They studied immigrants from ten different cultural backgrounds in Canada and Israel by carrying out fifty-four interviews with immigrant fathers and investigated immigrant fathers' perception of fatherhood in the midst of cultural

change. The study challenges the widely held view that immigration itself is a risk factor for fatherhood. It focuses rather on the systemic barriers and obstacles facing immigrant fathers in their new country and the opportunities this change presents. Fathers who had escaped from political dictatorships offered positive reports that they were living safely in a host country. This was considered to be an opportunity to reinvent themselves as fathers and men. Fathers were found to be highly present, involved and motivated to express their roles as fathers in a new country, seeing their primary role as the breadwinner and taking responsibility for the well-being of the family.

However, a limitation of this study was that there was no non-immigrant comparison group; this would have helped to determine whether non-immigrant and immigrant fathers shared similar experiences or contrasting thoughts about their role. Furthermore, research on immigrant fathers may be difficult to conduct because they may be unwilling to participate in research due to their legal status. This may be one contributing factor as to why little is known about this minority group of immigrant fathers and father-child relationships (Bronte-Tindew, Moore, Capps & Zaff, 2006). It is also difficult to control for sample bias, as fathers may magnify involvement with their children, making their responses more socially desirable (Lewis-Beck, Bryman & Liao 2003).

In relation to HIV, immigrant fathers may have to negotiate multiple cultural identities. They may experience isolation and disclosure fears, if they have a diagnosis of HIV (see section 1.3.1) within an environment of cultural discrimination (Osella & Osella, 2000).

### **1.5.3 Summary.**

Although research relating to immigrant fathers is sparse, two perspectives have been developed. The deficit perspective sees immigration as a source of stress. Here fathers adapting to cultural changes, in the host country is seen as a factor that can negatively impact on the quality of their relationship with children and partners, particularly if their children and partners adapt more readily to the norms of the host country. All of these factors can be further complicated by a diagnosis of HIV. There is a gap in specific research related to this. If fathers are reunited with their children in the host country, attachment concerns have been reported with children

withdrawing from their fathers. Lack of rights, unemployment and anti-immigration policies can add to the burden of being an immigrant father. These factors can challenge their masculine identities and impact on the quality of their relationship with children and partners.

Conversely, the generative-resilience perspective views immigration in a positive light, particularly for those who have experienced dictatorship and political persecution. Having successfully arrived in a democratic host country, it has helped them to foster a sense of safety and opportunity. Which model is relevant, is dependent on a number of factors, such as pro-immigration policies, cultural conflicts, that may result from fathers' desires to maintain their traditional family roles contrasting with those of the host country. It is important to study immigrant fathers in the context of their country of origin, political standing, family systems, community and cultures. The situation may be further complicated with black African fathers who have some children remaining in Africa and others in the host country, especially in relation to HIV disclosure decisions.

### **1.6 Parental HIV disclosure.**

Disclosing parental HIV status to children is often a significant challenge and a dilemma for HIV-positive parents. Serovich, Lim, and Mason (2008) describe two theories of disclosure in relation to parents' HIV disclosure to children. The disease progression theory assumes that disclosure is related to stage of illness. Here disclosure occurs when the physical symptoms of HIV become visible and therefore can no longer be kept secret. This may mean more hospital visits and/or changes in CD4 count. Alternatively the competing consequences theory (Serovich, Lim, and Mason 2008), focuses on environmental influences, social support, stigma and the child's isolation. This theory suggests that the relationship between disease progression and disclosure is determined by the probable consequences resulting from the disclosure. These theories were delineated from a qualitative study of 125 female African American participants. It was carried out retrospectively but tracking women from diagnosis to disclosure may have been more informative as it would have included the process of disclosure. This study used a small sample size and only focused on women. A larger study, including male participants may have made findings more representative (Serovich, Lim, and Mason 2008).

A global literature review undertaken by Qiao, Li & Stanton (2013) found that there were a number of mediating factors that determined parental HIV disclosure to children. Studies showed that some parents disclosed to children because of their own psychological and parenting needs (see Pilowsky, Sohler, & Susser, 2000, Rwemisisi, Wolff, Coutinho, Grosskurth, & Whitworth, 2008; Thomas, Nyamathi, & Swaminathan, 2009). There were concerns that children would learn about parental HIV infection from other family members, friends, and or by other means (Dane, 2002). Some parents disclosed their infection when they could not bear to keep their illness a secret (Pilowsky, Sohler & Susser, 2000). Other parents decided to tell children about their HIV status in order to obtain support from children. Others wished to educate their children about the risks of contracting HIV, such as practicing unprotected sex and drug use (Dane, 2002; Nam, Fielding, Avalos, Gaolathe, Dickinson & Geissler, 2009).

However, this review did not include non-English language articles or unpublished studies. Some studies did not specify that they had focussed on parental HIV disclosure to uninfected children. Half of the quantitative studies involved no more than a hundred respondents and measurement of disclosure practice was very general, thus making it difficult to differentiate the features of various types of disclosure such as partial, full, forced, planned and unplanned disclosure. The lack of standard measurement also makes it difficult to compare results across studies. Reliance on conventional medical measures and the use of broad categories such as HIV or AIDS may not accurately capture disclosers' perception of their own disease state. Results may also show that disease stage is unrelated to disclosure (Letteney, 2012).

#### **1.6.1 Paternal HIV disclosure.**

Armistead, Klein, Forehand, and Wierson (1997) found, for HIV-positive fathers with haemophilia, disclosure to children was related to the child's age and to fathers' poor health. Lee and Rotheram-Borus (2002) found HIV-positive fathers were less likely than mothers to disclose earlier in the disease course. Letteney (2012) focussed on fathers' disclosure of HIV to their children, she found that fathers were more likely to disclose to older rather than younger children, regardless of the children's gender. The finding supports earlier research (see Lee & Rotheram-Borus, 2002; Simoni,

Davis, Drossman & Weinberg 2000). Overall, findings suggest that disclosing fathers with HIV disease may have unique characteristics related to disclosure. In Letteney's (2012) study, those disclosing their HIV status were more likely to be unemployed, accessing some social support and presenting more HIV-related symptoms. This study was exploratory and correlational, measuring all variables simultaneously. This study is limited in size and generalisability, because it prohibits inference of predictive factors for disclosure. As studies have been qualitative in nature, causal factors of disclosure have not yet been fully identified.

### **1.6.2 Summary.**

Findings from the research reviewed here, support both the disease progression and competing consequences models of disclosure, while overall findings were mixed. Possible reasons for this could have been because disclosure may have yielded different meanings in studies (Pilowsky, Sohler & Susser, 2000, Kennedy, Cowgill, Bogart, Corona, Ryan, Murphy & Schuster, et al 2010, Murphy, Roberts, & Hoffman, 2003, Vallerand, Hough, Pittiglio, & Marvicsin, 2005). Some of the mixed findings might have derived from variations in methodology including sampling and outcome measurement. Many studies failed to identify or control for individual and contextual factors that could potentially mediate or moderate the impact of disclosure or nondisclosure. Future studies will require the use of standard measures, allowing for a comparison between maternal and paternal disclosure. Future disclosure studies need to take into account the cognitive development of children in terms of HIV disclosure to help parents make disclosure in developmentally appropriate ways.

### **1.7 Adjustment to HIV.**

The discussions in relation to HIV are complicated by disease related stressors such as migration, stigma, social and political inequalities as well as unhelpful connotations of masculinity and fatherhood. It is probable that adjustment to a diagnosis of HIV can be unique for black African fathers. Exploring adjustment on a broad basis, Gerhardt (1989) identifies two sociological approaches which look at personal identity and the onset of chronic illness. The 'crisis model' is predominantly associated with the effects of stigma and labeling. The 'negotiation model' in contrast focuses on the emergent nature of the chronic illness experience. Living with a chronic illness is seen as representing a potential loss of self in which a person

struggles to maintain 'normality' overtime in the face of uncertainty. Bradley's (1997) Generativity Status Model stipulates that individuals may have to negotiate levels of involvement and inclusivity within their own communities and wider society for black African men, as immigration can result in loss of family/social support which can impact on generativity. Rejection caused by the stigmatising identities that are held by men can heavily influence what they can achieve. This is a bi-directional process which is influenced by rejection caused by stigma and inequalities. It affects the cognitive, social and biological factors that create subjective life experiences. Adjustment as a result of disclosure or non-disclosure may mean redefining relationships with family and the wider community.

The meaning of chronic illness is not only personal but is a shared experience consisting of interactions with others. Adjustment could mean redefining ideas of what is 'good' or 'bad' and considering positive aspects of one's life to lessen negative aspects of illness. Bury (1991) focuses on the 'problems' associated with living with a chronic illness, emphasising the potential for an 'active coping' response to chronic illness utilising Corbin and Strauss's (1991) notion of 'comeback'. This concept has two dimensions. The 'physical' dimension refers to the active work (as against a passive response) engaged in by the patient when undergoing medical treatment and rehabilitation. In contrast, the 'biographical' dimension refers to the attempt by the patient to reconnect to their life prior to diagnosis and also with the present and future. Bury employs the term 'coping' in its relativistic sense, that is in terms of different kinds of adaptation rather than the normative use of 'successful' or 'unsuccessful' responses to living with a chronic illness. The Cognitive Adaptation Model (Taylor, 1983) states that adjustment centers around three themes: 1) a search for meaning in the experience; 2) an attempt to regain mastery over the event; 3) enhancing self-esteem. However given the unpredictability of HIV and social responses to the disease, regaining mastery may be difficult.

### **1.7.1 Post-traumatic growth.**

Positive changes following a negative life event can occur, such as adopting new priorities and holding a new outlook on life. This is known as post traumatic growth (PTG). The meaning component of Taylor's (1983) Cognitive Adaptive Model therefore has the most overlap with PGT, where individuals rethink attitudes and



priorities along more gratifying lines. The initial reduction of the feeling of invulnerability after trauma appears to play an important role in subsequent growth. Here a person is able to focus on existential matters for example, what is important to them in their life through critical reflection and rumination of important issues. The Socio-emotional Selectivity Theory (Carstensen, Isaacowitz, & Charles, 1999) suggests that when time is limited and is at a premium or perceived to be at a premium, short-term emotional goals such as a desire to spend time with friends and family take priority.

A study by Milam (2004) conducted a longitudinal study found that 59% of participants reported moderate to high levels of PTG following a HIV diagnosis. This was a large scale quantitative study, incorporating a number of measures such as health, optimism/ pessimism, PTG, religiosity and medical information. Findings were based on self-report questionnaires therefore social desirability and recall error need consideration in relation to the validity and reliability of this study. Furthermore other factors that may have facilitated PTG such as counselling, psychotropic medication, and alternative therapies were also not included. A systematic review was carried out by Amos (2015) on qualitative studies concerning PTG. Findings revealed that those living with HIV experienced PTG within five domains: 1) improved relations with others; 2) identification of new possibilities for one's life; 3) increased perception of personal strength; 4) enhanced appreciation of life; 5) spiritual growth.

### **1.7.2 Religion and spirituality as a key facilitator for growth.**

In line with PTG theory, perceptions of diagnosis research have indicated that individuals often turn to religion and spirituality when coping with change and difficulties (Dein & Stygall, 1997; Doyal & Anderson, 2005). Faith and traditional sacred beliefs are often important to people from African communities in the UK and they are more likely than other ethnicities to identify as belonging to a religion (Dodds 2006). Religion can contribute to the controllability and positive reframing of an illness (Pargament, Smith, Koenig & Perez, 1998), as well as a sense of meaning (Frankl, 1959; Jenkins, 1995). Furthermore, those diagnosed with HIV who engage in spiritual activities, report lower emotional distress (Sowell, Moneyham, Hennessy, Guillory, Demi, & Seals, 2000), greater optimism (Biggar, Forehand, Devine, Brody, Armistead, et al, 1999) better psychological adaptation (Simoni, Kurth, Pearson,

Pantalone, Merrill & Frick, 2006) and greater control of CD4 count (Ironson, Stuetzle, & Fletcher, 2006).

Chinouya and O'Keefe (2005) found that some UK-based Africans believe that prayer can cure HIV without medication and that religious beliefs can prevent HIV transmission. Despite faith being strongly associated with their ability to cope with HIV, the church was at times viewed as a threatening place, where confidentiality was undermined and stigma generated. However this study consisted of 22 participants, based in one town. HIV services here were in the initial stages of development at the time of the study and therefore, those with HIV may not have had sufficient access to information about HIV. Therefore their beliefs that having faith can cure, or prevent HIV could have been left unchallenged and findings may not be representative of those living with HIV in other areas of the country.

Additionally, Fakoya, Johnson, Fenton, Anderson, Nwokolo, et al. (2012) surveyed 246 Black African newly diagnosed HIV positive men and women in London. They found that religious belief do not act as a barrier towards HIV medication adherence. This study is more recent and conducted with a larger sample, in a city where HIV services are well established. The participants had access to information, gained knowledge about the routes of transmission and knew the value of adherence to medication regimes.

### **1.7.3 Summary.**

Adjustment to an HIV diagnosis can be difficult and several adaptation models have been developed to understand the process. However there are a number of individual, biological, cognitive, social and psychological factors that combine with wider social inequalities that make it difficult to think about adjustment in a linear and definitive fashion. This is especially true of HIV, given the unpredictability of the disease and the social responses to it.

Nevertheless, research does exemplify that PLHIV can experience growth following their diagnosis. Here they re-evaluate their priorities and develop personal strength and religion and spirituality can play a significant part in this process.

Overall, research on PTG appears to be relevant to the field of counselling psychology because psychologists may benefit from increased awareness of the

potential of PTG to occur amongst clients who have HIV. By adopting a focus on growth or positive aspects of functioning, psychologists may be able to enhance a person's own ability to facilitate change in their lives and foster growth. This may be considered as a different intervention to those designed to alleviate distress (Amos 2015).

### **1.8 Rationale for the current study.**

Global health inequalities have meant that HIV infection has had a devastating impact on Sub-Saharan Africans, where infection rates remain high and resources are limited. Many Africans living in the UK have witnessed misery and suffering caused by HIV. Therefore, even though HAART medication is available in the UK, many are faced with difficult and complex choices to make, influenced by their cultural and social standing. This review has documented research into biopsychosocial phenomena that impacts on black African communities living with HIV in the UK, focusing specifically on black African men and fathers where relevant and possible. As a result, it has highlighted gaps in research in relation to the impact that migration has on this population, as well as the disease related stressors that men, in particular, cope with. These concern stigma, masculine identity and stereotypical notions of fatherhood that form part of the overall complex phenomena experienced by men with parental responsibilities. These studies took place, in the main outside of the UK and therefore it is unclear how men negotiate their identities amidst a morass of variables, particularly in light of a HIV diagnosis in the UK. The meaning making of HIV positive black African men who have parental responsibilities in the UK, is therefore worthy of attention (Larkin, Watts & Clifton, 2006).

#### **1.8.1 Relevance to counselling psychology.**

Counselling psychologists hold humanistic values and view human experience as dynamic, embodied and relational in nature. As a result we strive to adapt a critical, reflexive and flexible approach to traditional psychological theory. We are well placed to make ourselves knowledgeable about diverse life experiences and needs of people we come into contact with because we pay attention to social context, by thinking about diversity and inequalities and how these manifest in wider society and thus in our practice. (BPS Professional Practice Guidelines, 2005). Counselling psychologists use themselves within their therapeutic work, bringing their knowledge,

experiences and self-awareness to their interactions with others. They are also committed to making a contribution to scientific, empirical enquiry, whilst holding our values. This study is therefore pertinent to counselling psychology because it aims to inform practitioners of the broad issues impacting on this population, so that therapeutic interventions can be adapted and integrated into existing service provision to meet the needs of this unique and under-researched group.

### **1.9 Aims and research question.**

This study aims to give voice to a marginalised group by engaging with individual subjective lived experiences. Black African HIV positive fathers are a unique group whose needs may currently be going unmet within services because of the lack of insight and knowledge into their own unique personal experiences.

The main research question is therefore:

*'What are the lived experiences of black African HIV positive fathers living in the UK?'*

## **CHAPTER 2**

### **METHODOLOGY**

This chapter provides details of the philosophical and theoretical underpinnings of Interpretative Phenomenological Analysis (IPA). It contrasts IPA with narrative approaches such as Discourse Analysis (DA) and Critical Narrative Approach (CNA), giving a rationale for the use of IPA in this study. The latter part of the chapter takes the reader through the recruitment process, the ethical considerations taken into account in this study, data collection and analysis, as well as the steps taken to ensure trustworthiness and reliability of the study.

#### **2.1 Qualitative approach utilised.**

Research methods are used to gather data in qualitative and quantitative forms. Collecting quantitative data means that a measurement of variables takes place to verify existing theories and hypotheses, or alternatively, to refute them and/or generate new hypotheses. Phenomena are investigated based on gathering observable, measurable data and using statistical analysis to generate, empirical evidence, an approach which pertains to the positivist branch of philosophy (see Wisker, 2007). Quantitative methods are not always appropriate for understanding meanings, beliefs and experience. An exploration of phenomena from this perspective requires qualitative inquiry, as this provides rich descriptions of the phenomena under investigation via a small sample (Smith & Dunworth, 2003), whilst paying attention to the unique variation of experiences, interpersonal issues, meaning, context and culture. This is relevant if the research subject is complex or under researched, because unexpected findings are able to emerge (Barker, Pistrang & Elliott, 2002).

IPA is informed by three main areas of philosophical knowledge. Phenomenology is essentially concerned with consciousness as experienced first-hand by individuals (Smith, Flowers & Larkin, 2009). Hermeneutics considers how people make sense of and interpret certain experiences (Larkin, Watts & Clifton, 2006). Finally, ideography is concerned with understanding the meaning of individual life and how particular, experiential phenomena have been understood from the perspective of particular people (Smith, Flowers & Larkin, 2009).

### **2.1.1 The philosophical underpinning of IPA.**

Four phenomenological philosophers have been key to informing the development of IPA; they are Husserl, Heidegger, Merleau-Ponty and Sartre (Flowers, Smith & Larkin 2009). Husserl attempted to identify key structures and features of human experience and suggested that we put to one side or 'bracket' off our assumptions and focus on our perceptions of the world through engagement in a series of reductions. By looking at phenomena through different lenses, it is possible to think about phenomena differently. The concept of consciousness is important as Husserl proposes bracketing off the whole question of whether a reality exists that is separate from us and our thoughts. Indeed the term 'reality' is derived from a verb which means to 'think'. Therefore according to Husserl, adopting the 'phenomenological attitude' involves turning our gaze towards how the object appears to consciousness (Shinebourne, 2011).

However Heidegger questioned the possibility of the existence of knowledge outside of the interpretative stance. Heidegger used the term 'person in context' because we are situated in a meaningful world, we observe, think, feel and engage. We are not able to fully escape the pre-conceptions we have when experiencing a particular phenomenon (Flowers, Smith & Larkin, 2009). "Every interpretation is already contextualised in previous experience and can never be 'presuppositionless'" (Shinebourne, 2011, p4).

Merleau-Ponty shares both Husserl's and Heidegger's commitments to understanding our being in the world. However, where Heidegger addressed the issue of our existence being an intrinsic part of being in the world, Merleau-Ponty developed the idea of the embodied nature of our relationship to the world, the body is essentially the vehicle/means of communicating with the world (Flowers, Smith & Larkin, 2009). In contrast, Sartre advocated that existence comes before essence. The self is not a pre-existing entity to be discovered, rather the self unfurls in particular contexts, influenced by the historical, biological and social climate in which a person operates. Sartre, by thinking about personal and social relationships, also extends Heidegger's contribution, in that we are better able to conceive our experiences as contingent upon the presence and/or absence of our relationships to other people (Flowers, Smith & Larkin, 2009).

### **2.1.2 The theoretical underpinning of IPA.**

The theoretical application of Heidegger, Merleau-Ponty and Sartre's phenomenological and existential perspectives, is that the person is viewed as being embodied and embedded in the world, in particular in a historical, social and cultural context. In the context of psychology, the emphasis is placed on exploring the human lived experience and the meaning that people attribute to their experiences (Morgan, 2007). When exploring phenomena that influence the formation of self-identity, subjective life experiences and interactions between cognitive, social and biological factors need recognition, thus this study is underpinned by critical realism (Bhaskar, 1975). Meaning is derived from interpretation and IPA considers phenomenological inquiry as an interpretative process (Heidegger, 1962). Phenomenology requires the uncovering of meanings concealed by the phenomenon's mode of appearing. Heidegger links phenomenology with hermeneutics. How things appear or are covered up must be explicitly studied and made manifest through interpretation, communicated by Heidegger's concept of 'logos' meaning discourse and discourse is expressed through language. Discourse is immersed in the context of being in the world and every interpretation is already grounded in fore-conception (Shinebourne, 2011).

IPA in this context also recognises the role of the researcher, in the sense-making process. Smith (2004: p 40) refers to this as a double hermeneutic process: 'the participant is trying to make sense of their personal and social world, the researcher is trying to make sense of the participant trying to make sense of their personal and social world'. Ontologically, the researcher is aware that phenomena are there to be discovered, however the researcher inevitably influences the process. The critical realist perspective recognises that there are different and valid perspectives on reality and phenomena. They are perceived and experienced in a fluid and subjective way depending on individual beliefs and expectations. This perspective therefore recognises an inherent subjectivity in the production of knowledge (Bunge, 1993).

Guba and Lincoln, (1994) considers research data, such as the accounts of research participants, to be 'constructed' within a particular research context, rather than as an objective reflection of 'reality' (Shotter, 1993). The participant and researcher are

interdependent and embedded within history, context, culture, language, experience and understanding (Wilkinson & Kitzinger, 1996).

Epistemologically, the process of interpretation is dynamic and iterative. Engagement in the hermeneutic circle is an interplay between parts and the whole and between the object and the interpreter (Shinebourne, 2011). Through an iterative process of each case with a move to produce detailed accounts of patterns, meaning and reflections, different aspects of a particular account can be explored. It is therefore possible to learn a great deal about a person in a particular context (Shinebourne, 2011).

Thematic analysis (TA) is also a method for identifying, analysing and reporting patterns as 'themes' across data sets (Braun & Clarke, 2006). However it does not always employ the same emphasis on reflexivity and interpretation as IPA (Braun & Clarke, 2006). Grounded Theory (GT) utilises large samples and looks to develop a theory gained through the process of saturation and the samples are heterogeneous rather than homogenous as with IPA. GT also utilises a more reflexive approach, through memo writing and the use of diaries. IPA uses a Heideggerian approach to reflexivity that employs a phenomenological attitude and the hermeneutic circle, with a focus on how people make sense of their experiences (Smith, 2004).

### **2.1.3 IPA in contrast to narrative approaches.**

Narratives are created through stories of lived experiences (Ricoeur, 1985) and the meaning people give to their experience. It is a way of making sense of the ambiguity and complexity of human lives (Bruner, 1986). Narrative analysis takes into account the relationship between individual experience and cultural context (Claninin & Connelly, 2000). There are different forms of narrative analysis, with some focussing on the content of stories and others focussing on meaning or both content and meaning. Narratives can be analysed using concepts derived from theory, such as, Discourse Analysis (DA) and Critical Narrative Analysis (CNA).

Discourse analysis draws upon linguistics to assess how people construct accounts of experience. Discourse analysis (DA) emerged during the late 1980s as a radical critique of (then) mainstream social psychology and social cognition. Most types of



DA tend to focus upon the function of language within specific contexts. Like behaviourism, DA limits its focus to the observable, in this case, linguistic behaviour and rejects the notion of cognition (Potter and Wetherell, 1987). Its approach demands a discursive psychology and constructs a textual ontology. For discourse analysts, links between discourse and 'real'-world actions are difficult to make, as the 'real' world can only be understood as a construction (e.g. see Edwards, Ashmoor & Potter, 1995). DA has proved itself to be a powerful deconstructive tool, but is still unsuitable to offer viable bases for intervention in the world (see Nightingale & Cromby, 1999; Willig, 1999). IPA is sensitive to participants' cognitive and affective reactions and utilises language to understand how participants make sense of their experiences (Braun & Clarke, 2006). Similar to IPA, Critical Narrative Analysis (CNA) is grounded in the phenomenological tradition (Langdrige, 2008).

The need for interpretation, as stressed by Heidegger, was fully realised in terms of epistemology and methodology by Gadamer and Ricoeur. Ideas from these two philosophers have been particularly influential in the most recent developments in phenomenology. Most significantly, in the use of the phenomenologically informed narrative methodologies (Langdrige, 2008). In relation to CNA, Gadamer and Ricoeur place a strong emphasis on the way in which experience is mediated through language, proposing that it is through language that understanding occurs. Through language, it is possible to gain an understanding of the 'things in their appearing' (Langdrige, 2008). Ricoeur also recognises existence as being embodied and as preceding language. Ricoeur understands the need for hermeneutics so that existence can be revealed through language (Langdrige, 2008).

CNA applies two distinct types of hermeneutics, empathy and suspicion. A hermeneutic of empathy is familiar to much of phenomenology and involves the application of seeing the world, our pre-understanding, to text, in order to ascertain meaning. Hermeneutics of suspicion in contrast, involves the application of methods of interpretation that are outside the text. Freudian, Marxist and Niezschean theories were the key hermeneutics of suspicion identified by Ricoeur (Langdrige, 2008). Langdrige follows Ricoeur's approach, including both analysis grounded in participants' accounts, the hermeneutics of meaning recollection and at the same time another layer of analysis grounded in the specific hermeneutics of suspicion.

The analyst aims to gain an alternative view grounded in broader socio-cultural discourse which may contradict or complement understanding but not replace claims distinguished through empathic understanding (Smith, 2004). This approach is therefore teleological rather than archaeological, so that analysis may offer new understanding. CNA is a form of critical social psychology and is based on social theory (Langdrige, 2008).

CNA occupies a similar ground to the notion of multiple levels of interpretation in IPA, where empathic reading is likely to come first and may be qualified by a more critical and speculative reflection (Smith, 2004 p46). One problem with using descriptive phenomenology is the absence of participants' voices from the final account of the phenomenon under analysis. In IPA, the importance of attending to the participant's language is accommodated at least to some extent by including quotations from interviews to retain some of the specific distinctions and textures of individual voices. IPA is concerned with the examination of meanings which people impress on their lived experiences. This meaning may illuminate the embodied, cognitive, affective and existential domains of psychology (Smith, 2004).

#### **1.4 Rationale for the use of IPA in the present study.**

Black African fathers living with HIV in the UK is significantly under researched group and therefore little is understood about their experiences. In the context of HIV/AIDS, Doyal, Anderson & Paparini (2009) suggested a need for further qualitative studies that investigate African men's experiences of living with HIV. IPA, due to its philosophical foundations has been selected as an appropriate and suitable methodological approach for analysis. IPA, with its phenomenological focus explores subjective experience and is therefore an appropriate methodology to apply to a study of the lived experiences of black HIV positive fathers living in the UK. It is able to tap into participants' own particular experiences and perspectives, and draw upon this information to help to elucidate how they have experienced HIV. IPA is uniquely positioned to explore the complex constellation of factors that have impacted on the six men in this study. It may be used to investigate the way in which they came to terms with their HIV diagnosis, and how they began to integrate this into their embodied and experiential self-identity in respect of their role as fathers. Although this study recognises that language and social interaction play a role in the

conceptualisation of identity, it is not completely dependent on linguistic structures. Parker (1992) highlights a capacity to be reflexive as central to human agency and understanding, maintaining that reflexivity is the 'point of connection between the individual and the social' Parker 1992, p105). IPA aims to bridge the division between cognition and discourse (Smith & Osborn, 2008).

There are a number of ways that data can be collected for an IPA study, such as diary extracts, focus group discussions and interviews. The present study utilised interviews (for a discussion on the limitations of this method of data collection for the present study, please see section 5.3). The purpose of an IPA interview is to facilitate each participant's recall of parts of events that form their overall lived phenomenological experience. Qualitative methodological approaches identify these from data that reflect a common understanding of a particular phenomenon. IPA transcripts were analysed for relevant themes and repetitions of recurrent themes were taken as indicative of their status, reflecting shared understandings. In keeping with the essence of IPA, and its focus on interpretation, the selection of recurring themes was based on the researcher's interpretation, in order to engage with the text (Smith, 1996).

## **2.2 The Recruitment process.**

The researcher approached HIV charities in two major cities in the UK. The charities were contacted once the University of Wolverhampton School of Social Sciences (SAS) student management board had accepted the research proposal and the University of Wolverhampton Behavioural Sciences Ethics Committee (BSEC) had granted the research ethical approval. Further ethical considerations are discussed in section 2.5. The research information sheet (see appendix A) was given to managers of the HIV charities. This was followed by a face to face meeting to discuss the recruitment of appropriate participants. Subsequently, posters were displayed within these charities to publicise research (see appendix B).

### **2.2.1 Participants.**

Six ( $n = 6$ ) participants were recruited for this study. IPA uses small, purposively selected samples (Smith, Flowers, & Larkin, 2009). The participants selected identified themselves as black African men who had migrated to the UK. They were over the age of 18 and had one or more biological child for whom they had parenting

responsibilities. The mean age of their children was 24 ( $m=24$ ). Participants were aged between 50-62 ( $m= 53$ ). Their residency in the UK ranged from 19 to 9 years ( $m=13$ ). Time since diagnosis ranged from 10-20 years with a mean of 15 years ( $m=15$ ) since diagnosis. Five men were married and one was divorced. They had a range of employment, educational qualifications and were from a variety of religious and cultural backgrounds. Their counties of origin included Uganda (East Africa), Sudan, (North Africa) and Zimbabwe (South Africa). Five men had reported that they had come to the UK due to the political unrest in Africa. One arrived for work and study opportunities. Please refer to appendix C for participants demographic details.

### **2.2.2 Inclusion and exclusion criteria.**

Managers of the charities triaged potential participants; this meant that those with a good level of spoken English, those with no current known mental health or substance misuse challenges were selected for the study. Those with a new diagnosis of HIV were excluded from the research, on the grounds that they may be processing this knowledge and may therefore not have been in a position to think about and discuss some of the areas included in the interview schedule.

### **2.2.3 Homogeneity of the sample.**

To keep the sample homogenous, it was planned originally that black African men with children residing in the UK would be recruited. However this was a very small sample population and it proved difficult to acquire. Consequently, black African men with children in the UK and Africa were recruited. The study maintained homogeneity by including participants with biological children only. IPA utilises small, purposive samples that are carefully situated because of its primary concern with the acquisition of detailed individual accounts of experiences (Smith, Flowers & Larkin, 2009). The recruitment of participants ended after six interviews to maintain the focus on the perspectives of a small number of individuals.

## **2.3 Development of the interview schedule.**

The interview schedule was based on a review of related literature and the researcher's own interests in finding out about the significance of an HIV diagnosis for black African men and the impact that this has on their identities as men and fathers. The open ended questions were broad and this provided the opportunity for

participants to lead discussions in areas pertinent to them, within the context of three main areas.

The opening questions explored how participants came to find out about their diagnosis and what the diagnosis meant to them. These questions were aimed at eliciting information about their self-identity following diagnosis. The factors that influenced possible changes in their sense of self, as well as the thoughts they had about themselves in relation to HIV prior to the diagnosis. These questions were designed to explore whether the meaning of HIV had changed and what facilitated that change. As well as the adjustments they made, if any, following diagnosis. The coping mechanisms they have adopted, which may be internal or external.

The second part of the interview was designed to extract information from participants about their role as fathers to children here in the UK and abroad. To explore changes in their roles since migrating to the UK as well as how this has influenced the father-child relationship. This also included questions concerning disclosure and how fathers felt about their decision making regarding the disclosure of their HIV to children.

The summarising questions towards the end of the interview were designed to gain an understanding of the type of information fathers would have liked to support them and their families better. This included whether they had any advice or knowledge that they would like to pass on to men who were in similar positions as themselves. The final question aimed to determine whether participants experienced their social world (context) as being understanding of their needs.

The interview's provisional structure was designed to be broad enough so as to provide insight into the participant's unique idiographic experiences, whilst also taking an approach to encourage answers appropriate to the intended research questions (please see appendix D for the interview schedule).

The questions in the study protocol were reviewed by the research supervisor (NG) before being submitted to The University of Wolverhampton's Behavioural Sciences Ethics Committee meeting for ethical approval.

## **2.4 Interview procedures.**

The researcher met with participants at a time suitable for them at the local charities, a specific room was allocated for interviews to take place. This room was consistently used for interviews. Participants were given information about the research in the form of the information sheet. Details of the research were reviewed again with each participant to verify that they had been given this information and that they understood exactly what was required of them. Following this, participants were required to sign a consent form (see appendix E) and complete a demographic form (see appendix F). The interviews and engagement with participants were conducted in accordance to "Code of Ethics and Conduct" provided by the British Psychological Society (BPS) (2009) and Health Care Professionals Council guidelines ( HCPC, 2008, 2009)

## **2.5 Ethical considerations.**

All participants were informed that they had the right to terminate the interview at any point and they were encouraged to be open and honest about giving answers. Confidentiality was explained in detail therefore they were informed that all identifiable information would be removed from the transcripts. Their name would be replaced with a pseudonym and all confidential information pertaining to the research would be retained in a locked draw or electronically on a password protected device. It was made clear to participants that the research was independent and therefore there were no conflicts of interest. Further, the researcher was not known in the local black African community and was impartial.

Participants were given time prior to the interview commencing to settle, tea was made for them and snacks were provided this encouraged rapport building between the researcher and each participant. Participants were given the opportunity to arrange the room, how they wished and they were asked to place the Dictaphone where they wanted it. These steps were undertaken to ensure that participants felt comfortable and in control of the interview process. Please see appendix G for details of the duration of each interview.

Although probing questions were asked, the participants were given the option to elaborate further and add more details if they wished too, they were informed that

they could reserve the right not to answer questions or expand upon the answers they had given. Part of the study touched on participants' experiences in Africa this ran the risk of participants talking about their experiences of violence and torture. The researcher was careful not to ask direct questions in relation to this. Any information disclosed by participants was carefully managed and an acknowledgement of difficult experiences was made, to ensure that these men had been heard. After this no further unnecessary probing questions were asked and the researcher moved onto the next question. Using her training, any symptoms of trauma, particularly dissociation, would have been picked up by the researcher and managed. Should any such occurrences have happened, the researcher would have terminated the interview and steps would have been taken to ensure that the participant was taken care of. There were always members of staff present and aware that the researcher was conducting 'sensitive' interviews should the researcher or participants have needed assistance.

Following the interview, participants were debriefed. They were asked about the interview process and whether they found any parts of the interview distressing. There was an opportunity for participants to ask questions and talk with the researcher about aspects of the interview if they wished to. Additionally an information sheet with local organisations and support line numbers was also given to each participant.

A debrief session also took place with the managers of the charities and researcher following each interview to update them on how the interview went (no specific details of participants' discussions were disclosed). Each participant had the opportunity to talk to the relevant charity manager following the interview. This ensured that any emotional distress that may have resulted was picked up and responded to, in a timely manner. None of the participants expressed distress during or following the interview. Transcripts of the completed interview were not sent to participants to check for accuracy as this was thought to go against the IPA concept of co-creation of data. A reflective diary was kept throughout the research process (see appendix H). Participants were also made aware that the outcome of the study would be disseminated to the charity managers and they would be able to access this via the charities.

## **2.6 Data analysis.**

The data was analysed in accordance with the suggestions of Smith, Flowers & Larkin, (2009). An idiographic approach was taken in the analysis of individual transcripts. Detailed accounts of each participant were developed. This enabled the researcher to further immerse herself in the data. Following the transcribing of each interview verbatim, individual transcripts were read and reread through an iterative process. This ensured that the researcher was maintaining her focus on the participant and their phenomenological experiences.

A three column table was created and the transcript was copied into the middle column. The next step involved initial coding of the text, commenting on the descriptive aspects of the text and underlining what the participant was describing. A linguistic focus on coding takes into account the language used by the participant, to produce a deeper meaning. Finally a conceptual focus enabled the researcher to engage with the transcript at a more interrogative level, introducing her own interpretations of the data, this was placed in italics. This exploratory coding resulted in a descriptive core of comments, with a phenomenological focus. The emphasis remained on the transcript and coding was carried out in the right-hand column of the table.

Interpretations and connections were made throughout the transcripts which then formed the foundations of the emergent themes. These emergent themes were placed in the left-hand column of the table. (See appendix I for the coding of Asante's table). The emergent themes were formed to summarize the meaning of participant's accounts and interweave them with the interpretation and understanding being reported by the researcher. These emergent themes were then re-read simultaneously with the transcript to ensure that they captured the essence of the participant's lived experience. They were then moved around to form clusters of related themes, similar themes were merged together and a master list was created, these master lists became subthemes. Through a process of subsumption, where an emergent theme becomes a master theme, four master themes were developed (see appendix J for an annotated worked example of a theme). Transcripts were assessed for oppositional experiences (polarisation) and also for narrative and contextual elements (contextualisation) (Smith, Flowers & Larkin, 2009). Appendix K



illustrates the present and absent themes for each participant, and calculates whether the theme is present for each participant in over half the cases.

A synthesis of the interpretative idiographic analysis of each participant was extracted from each transcript to uphold the phenomenological underpinnings of IPA. This enabled the researcher to report her idiographic understanding of each participant's lived experiences.

### **2.6.1 Reflexivity.**

All interviews were conducted by JP who has had extensive experience working with Black Minority Ethnic (BME) groups. Her work took place in an educational setting and therapeutic setting where she worked directly with asylum seekers and refugees. She has a strong interest in understanding the differing needs of minority groups and issues of equality and diversity that are crucial in the development and delivery of an appropriate needs based therapeutic service. Throughout her academic career, she has focussed on exploring the needs of marginalised groups, victims of crime, substance misusers and the mental health needs of BME groups. She has actively worked with both statutory and non-statutory organisations to address health inequalities and create care pathways.

Being of an ethnic minority group herself, she has had experience of discrimination and the aspect of HIV related stigma was of particular interest to her. Black men are often vilified for spreading HIV and not being available to support their children. The researcher was interested in giving voice to these experiences (see appendix L for a reflexive account relating of the research process).

The researcher also developed her interest in long-term health conditions within a primary care setting and its required psychological adjustment. This was further developed within a secondary care setting where she was seeing people with a variety of conditions including HIV. This, coupled with the above rationale, led her to become interested in this research area, particularly when black African men were not attending appointments after they had been identified as requiring psychological support. Having looked at some literature in this area, she became aware that research into black African fathers was very limited and this became the focus of her

research. The research was not aimed at directly understanding why black African men were not accessing psychological support, but to provide a wider and deeper understanding of their overall experience of living with HIV and the impact that this has on their roles as fathers. This subject is pertinent to counselling psychology because it will enable those working within the services to understand the overall, broad needs of this population so that appropriate adaptations to service provisions can be made as well as changes in policy to reach this group and better meet their needs.

### **2.6.2 Trustworthiness and transferability.**

In order to ensure trustworthiness, Guba (1981) constructed four main criteria that qualitative studies should meet to ensure rigor. These criteria are adapted from questions posed by positivists regarding concepts of validity and reliability in quantitative and naturalistic studies. These four criteria are credibility in preference to internal validity, transferability in preference to external validity/generalisability, is this a real word dependability in preference to reliability and confirmability in preference to objectivity.

To make certain that this research study met these criteria, the researcher followed the stages described in appendix M.

## CHAPTER THREE

### RESULTS

#### 3.1 Overview.

Semi-structured interviews with six black African HIV positive fathers were conducted and analysed using Interpretative Phenomenological Analysis (IPA). This resulted in the emergence of four master themes:

Responses to HIV- the demise of the physical and social self.

HIV stigma- 'They don't realise that it anyone can get it.'

Re-emergence of the self.

Fatherhood- a changing identity.

The themes presented in this chapter are one interpretation of the phenomena of black African fathers living with HIV. The themes were uncovered by the researcher engaging in a double hermeneutic process (Smith, Flowers & Larkin, 2009). These are subjective interpretations and it is acknowledged that another researcher may have elicited different interpretations from this data.

This chapter will explore the master themes as well as sub-themes. Quotes from participants will be used to illustrate their narrative. Although the four master themes were common across all six accounts, areas of significant divergence will be discussed.

### 3.2 Master themes and related sub-themes.

Master Theme	Sub Theme	Occurrence of Theme (number of participants for whom the theme occurred)
<b>The demise of the physical and social self</b>	Symptoms of AIDS "It means death, like a death penalty"	5
	"In Africa, you are left to die"	6
	"I had nobody"	5
<b>HIV stigma-'they don't realise that anyone can get it'</b>	"It's not safe to talk"	6
	"Accessing treatment and support isn't easy"	6
	"You tell them that you are HIV positive and you've built a wall around you"	3
<b>Re-emergence of the self</b>	Breaking the silence	6
	Intimacy is difficult-challenging the mythical stereotype	6
	Drawing support from the church	3
<b>Fatherhood- a changing identity</b>	Paternal HIV disclosure	6
	A Father's loss of authority	5

### 3.3 Introduction to the themes.

The four master themes provide an interpretation of how black African HIV positive fathers in the UK make sense of their experiences. The first theme, *'the demise of the physical and social self'*, highlights the onset of physical symptoms and the initial responses to their diagnosis. It outlines the factors that shaped the cognitive appraisal of their diagnosis, particularly in relation to their experiences of HIV in Africa and their separation from family members.

The following theme, *'HIV stigma, they don't realise that anyone can get it,'* explores the men's experiences of HIV stigma, both within their communities and wider society. It considers the meaning-making processes that they undergo and which shape their sense of self. This is of particular significance when looking at the third theme, *'re-emergence of the self'*. Here a turning point is discovered, where men begin to flexibly view their social and embodied experience of living with HIV. This relates to the construction of their identities that incorporates their HIV status, rather than one that tries to dissociate from it.

The final theme, *'fatherhood- a changing identity,'* discovers men's identities in the context of their role as fathers, encompassing the challenges and difficulties that they are presented with, particularly in the context of cultural differences and their HIV diagnosis.

Overall, resilience and coping emerged that enabled participants to recognise their life following an HIV diagnosis. Although this diagnosis inevitably changed their identities, the accounts revealed stages where they felt their diagnosis needed to be kept hidden in order to protect their identities. Here their diagnosis had defeated them and they felt the need to withdraw socially. This was complicated by their understanding of HIV in the context of their culture, race and ethnicity. Nonetheless, despite the adverse impacts of HIV, the men's accounts revealed inner strength and resilience in their ability to seek support and make life-style changes. It signified their sense of responsibility towards family and particularly their children. They recognised that their relationship with their children had changed due to their diagnosis and/or migration however they made efforts to maintain regular contact with them. The participants' ultimate desire was to be able to support advice and guide their children so that they would not have to face the same or similar difficulties as themselves.

### **3.4 Master theme one: The demise of the physical and social self.**

This theme captures the initial physical changes participants went through, that were deemed to be uncontrollable, persistent and unexplainable. This is because the symptoms were firstly misdiagnosed, leading to a lengthy period of uncertainty and deteriorating health. The eventual diagnosis was accompanied by experiences of shock, defeat and hopelessness. There was a sense that the men were waiting to die, compounded by their lived experiences of HIV in Africa and their isolation in the UK. It was hard for them to accept that medication would give them an opportunity to survive. There was conflict between the physical decline due to the infection, and the internal mental struggle to accept that medication could offer them an opportunity for survival.

#### **3.4.1 Symptoms of AIDS - "It means death, like a death penalty."**

This sub-theme revealed the uncontrollable physical symptoms that these men experienced. There was a sense that these men were not expecting a diagnosis of HIV.

**Bongani:** "I came to find out that I had HIV when I went to hospital here in the UK."

**Asante:** "Basically it was when I felt ill."

**Mehtab:** "I feel hot and sometimes sweaty...it didn't go away...after three, four months, I nearly die, I went to the big city and the doctors said you have HIV."

**George:** "Well I didn't know about it until I got sick, um...I got sick and I was coughing and I didn't know, I didn't know what was happening, I had blood coming out of my nose."

**Dayo:** "It was when I was first admitted into hospital. They suspected, since I was from Africa, that I had malaria...unfortunately there was no improvement at all. So the doctor came to ask me...can we do an HIV test?"

**Ekua:** "The doctor suspected that I might have malaria but when that subsided, I was still feeling sick."

#### Descriptive

Their bodies were changing; however doctors were not able to identify the cause of their physical decline initially. There was a lengthy period of time during which the men had no idea what was happening to them.

The knowledge of their diagnosis means that participants are expecting an imminent death much like a terminal illness. Although HIV has been reconceptualised as a chronic long term health condition, for these participants this did not seem possible or comprehensible.

### Interpretative

They were filled with fear and uncertainty. The diagnosis had destabilised the foundations of their 'taken for granted' sense of self, in which ordinary day to day events had become suddenly irrelevant. There is a sense of hopelessness on hearing about the diagnosis. The emotional response is one of shock.

**Asante:** *"I thought um there's nothing that I can do with my life, there's no more life..."*

**Ekua:** *"It was like a death sentence to me."*

**George:** *"He announced that I had HIV. (short silence) and it was really awkward...It's scary to know."*

**Mehtab:** *"It meant death, like a penalty death."*

**Dayo:** *"At that that time I felt that it was the end of my life."*

**Bongani:** *"They come each and every day, trying to tell you that you are not going to die tomorrow."*

Ekua and Mehtab describe their diagnosis like a '*death sentence*', a '*death penalty*', given out for heinous crimes, where people are incarcerated for a long period of time, their liberty lost, social contact severely reduced, they are waiting to die, not knowing when this will be. The future seems uncertain, frightening and lonely.

### Descriptive

For Ekua this is made worse by the fact that doctors did not inform him that they were conducting an HIV test.

**Ekua:** *"My suspicion was that maybe my malaria had become resistant...she said, when you came to complain about malaria, we ran an HIV test, you are positive. I was furious!"*

### Interpretative

Ekua was unaware that he had been tested for HIV, therefore he did not have an opportunity to give his consent to be tested. His rights had been violated. Understandably this angered him. His loss of control, powerlessness and a changing body added to his sense of helplessness. There is a sense that having a diagnosis of HIV is very disempowering.

Additionally, Asante and Bongani talked about their experiences of torture in Africa. They had escaped political persecution so coming to the UK was a lifeline for them.

**Asante:** *"The life that we lived in prison, the rape that we went through... from other prisoners and so on. It shamed us a lot, it shamed us a lot and um yeah being in the haze of dictatorship that want power above anything... during the arrest they would inject us with blood and everything and say to us 'we will kill you with a slow death or fast death, whatever you want.'"*

**Bongani:** *"I was beaten...all my clothes were covered in blood... I was attending a political meeting... money was sent to Africa for air tickets...I had treatment here in the UK."*

A deep sense of shame was felt by Asante because of the heinous crimes against him. The men were unsure whether they would escape persecution; already they had experienced threats to their lives. The HIV diagnosis compounded this experience and served as a reminder of the real threats to their lives back in Africa, of the torture and persecution they endured there.

The men's experiences of HIV in Africa appear to also have come to the forefront of their minds when discovering their own diagnosis.

#### **3.4.2 "In Africa, you are left to die."**

In a country where treatment and resources are scarce and where health care systems have experienced severe decline amidst the economic and political disarray, poverty, misery and people dying of HIV/AIDS is a daily reality. Understandably, if these men have witnessed this and experienced at first-hand losses, the fear that they will die in the same way too is very real to them. These



memories of their indigenous communities are strong and are exacerbated by learning of their own diagnosis.

**Dayo:** *"Because what I saw back home, people were dying, so I thought that that is the end of my life."*

**Asante:**... *"You are left alone to die and no one cares for you..."*

**George:** *"Back home it was very scary. You know the way they tell you...especially the medical people, tell if you get it... it will kill you tomorrow."*

**Mehtab:** *"Even the doctor said, maybe he gonna die within one or two years, cos' there was no medication at that time."*

**Ekua:** *"I knew there was no treatment at all...there people...families were burying people with AIDS."*

Additionally, those with HIV in Africa are viewed in a negative light, HIV is associated with promiscuity and homosexuality.

**Ekua:** *"If someone has got HIV, back in Africa... it is related to homosexuality, so it's things that people do not want to know about, promiscuity."*

**Asante:** *"I have been brought up in a country whereby the situation is has to, has to do with the idea that in order to get HIV men and women have to be promiscuous, that person who has looked for it."*

### Interpretative

Those who are diagnosed with HIV immediately panic, they become outcasts within their own communities. The physical degeneration of their bodies infected with HIV, advancing towards AIDS is clearly visible to others. The community perceives these physical signs as indications of 'immoral' behaviour and can lead to people being mistreated and/ or avoided. They are ostracised by the community and left alone. Here men appear to be expressing that a diagnosis for them holds similar meanings and connotations. Not only is their physical health in decline, their social self is also affected due to their isolation. There is a sense that the person remains alone with the problem 'you are left alone to die.' Even though medication is available, there is still uncertainty, fear and lack of control.

### 3.4.3 "I had nobody."

The majority of the participants were alone, away from home, in a foreign country and fleeing persecution. They had left their families behind. These trans-located men were trying to survive in a new landscape fraught with hostility and challenges. They were disorientated and disconnected from their cultural ties and family support systems.

**Asante:** *"I had left the whole family back home... being on my own... in a foreign land and that being the first time getting out of my own country."*

**Bongani:** *"I couldn't even remember where I was. I would ask where I am? And they would say you are here in the UK. I had no one here...nobody."*

**Ekua:** *"I was away from my family. It clearly took an upper hand on me, I had no one to console me."*

**George:** *"I stayed in hospital for some time. I didn't want to tell anyone. Cos I couldn't come forward, until I got used to it I was too scared..."*

**Mehtab:** *"Well my dad, he...said, 'you know what, don't tell anybody.'"*

#### Descriptive

Some men were away from their families when they learned of their diagnosis. Mehtab was with his father but despite this, he was asked to keep his diagnosis a secret. This is an example of the ways in which their social lives had been greatly reduced, mainly because they had migrated to the UK away from their families '*being on my own*,' '*no one here*,' '*away from family*'. Furthermore, the stigma caused by HIV, meant that they felt the need to keep quiet, to maintain a HIV free identity. This seemed important so as to maintain links with their communities and be accepted '*couldn't come forward*,' '*don't tell anybody*.'

### 3.4.4 Summary.

There appears to be a personal struggle when they internalise their diagnosis. Although medication is available, the men find it difficult to accept that they will survive. This is as a result of the negative perceptions of HIV held by themselves and others within their communities. From the point of the diagnosis these men recognised that their lives would not be the same, it impacted on their ability to come to terms with the diagnosis. The theme encapsulates their internal struggle to keep

the diagnosis a secret, adjust to the different social positioning of themselves as well as coping with their physical impediments, due to their illness. These are major factors that force participants to re-evaluate their sense of self.

### **3.5 Master theme two: HIV stigma, "they don't realise that anyone can get it."**

This theme is an extension of the above theme and captures the participants' experiences of stigma and their difficulties in coming to terms with their diagnosis within the context of their communities and wider society (Poindexter, Henrickson, Brown; Fouché & Scott, 2013).

#### **3.5.1 "It's not safe to talk."**

The cultural and social positioning of participants had become fragmented by their HIV diagnosis and this is illustrated in their narratives.

**Asante:** *"My community, it's got a very err it does not welcome many err it does not welcome people who are HIV positive."*

**Ekua:** *"African communities, they still think like HIV is not in their community."*

**George:** *"It's not safe to talk to people. They start prying and talk to people."*

**Bongani:** *"Um err, you know that time, that word, it was a word of secret. It was a word that was in the wardrobe...It was talked about only behind closed doors. "*

**Dayo:** *"To talk about it, it's hard you cannot just come and say, to talk to somebody that I'm HIV positive."*

**Mehtab:** *"People they don't know anything...I never talk about this...I know the stigma and that when they told me, I became isolated."*

#### Interpretative

All of the participants seemed to be reluctant to talk about their diagnosis because they feared becoming ostracised from their own communities. There is a sense that HIV is not discussed, it is shunned and avoided '*HIV is not in their community, 'it was a word of secret'*'. The participants appeared to be denying and disowning an aspect of them, they steadily withdraw from their collectivist community to avoid rejection. Their isolation means that their HIV identity becomes all encompassing as their social networks diminish.

### 3.5.2 "Accessing treatment and support isn't easy".

Due to their social isolation and the fear that others may find out about their HIV diagnosis, there is a sense that the participants have experienced both enacted and felt stigma (Scrambler, 2010). This greatly reduces their quality of life even though HIV medication helps them to survive. Their social world became difficult to navigate and felt stigma motivated them to pass as non-stigmatised members of the community. This reduces their likelihood of being the target of enacted stigma. This was evidenced in the men's reluctance to access HIV services and resources.

**Interviewer:** *"And how did you feel about accessing those services at the time?"*

**Asante:** *"Um I had some worries you know, facing some err other BME groups. I didn't feel I could trust them."*

**Mehtab:** *"I moved...from a tiny town...Even I go to hospital, people say, why I go there. So I moved...it is more crowded here."*

**Bongani:** *"Some they are shy. If somebody sees me, what will they think?"*

**George:** *"...People got to understand, maybe some people die because of non-treatment because they are scared of going for treatment."*

**Ekua:** *"My state of mind was not stable, I got a job here but then I lost it because I became an alcoholic...I did not apply for benefits, I was living off savings and even then I was ashamed to go and apply for benefits. I didn't do it..."*

#### Descriptive

These men describe the difficulties they had accessing treatment due to the shame and stigma they felt about their diagnosis. This feeling was persistent and pervasive, *'I moved,' I was ashamed to apply for benefits,' I didn't feel I could trust them,' my state of mind was not stable.'* Participants appear unable to identify with other aspects their identities. They are constantly thinking about their diagnosis and this understandably impacts on their psychological wellbeing.

**Interviewer:** *"When you have difficult feelings or worries, how do you cope with them?"*

**Mehtab:** *"Sometimes I go to the G.P. and he gives me tablets."*

**Dayo:** *"The moment you stay indoors...that's when you get depressed."*

### Interpretative

Finding out about their diagnosis created many challenges, Mehtab moved to a larger city in order to find privacy away from gossip and speculation. Taking responsibility for their HIV identity seems burdensome and too difficult to manage. A part of themselves wish to leave behind the stigma, prejudice and problems the diagnosis forced upon them but with every new morning it remained.

**Ekua:** *"I was still in hiding, not seeing anyone."*

**Assante:** *"There's no more life, I believed this for three years or more."*

**Mehtab:** *"I think how can I keep these tablets (HIV medication)? I'm thinking double to be friends with people from the same country. Because I think if they come home and check out...if medication time comes... they gonna be suspicious."*

### Descriptive

Although the HIV medication gave participants a chance to survive, the diagnosis has taken away the social aspect of their lives. Medication acts as a reminder of their diagnosis, it gives away their HIV status, leading to possible rejection. These men had come to the UK in search of a better future, a new life but instead HIV had diminished their hopes and dreams.

### **3.5.3 "You tell them that you are HIV positive and you have built a wall around you."**

This theme captures the lack of knowledge and awareness by health care professionals who work away from specialist HIV services. It highlights the impact this has on the lived experiences of participants.

**Ekua:** *"I was in hospital cos' of my diabetes, I was admitted and I wasn't carrying my HIV medication...I asked, 'is there an HIV consultant here?' because I needed medication. There was a change of shift and they moved me from a general ward into isolation, my wife came to hospital with my HIV medication, they asked her to put gloves on before entering my room."*

**Mehtab:** *"When the nurses come they talk, they laugh, but for us, she just want to do her work and then go. They don't talk, they are not friendly. It's a reminder that we have HIV."*

It is difficult to decipher whether it is HIV stigma that causes participants to think that they are being treated differently, or whether it is because they hold more than one stigmatising identity, being part of a minority group, refugees or asylum seekers. Nevertheless, there is a sense that they are being treated unfairly.

**Bongani:** *"If you are ashamed and afraid to go to hospital, because there are white people, who die, it's you. Although you will be treated by that white person, he will treat you, if you say, when I went there yesterday, he was angry, I don't want to go there today, who suffers, it's you."*

Bongani appraises the situation differently; he was aware of discrimination and seemed to have experience of it. He questions whether it is HIV related discrimination this is because the discrimination has not been made explicit. Additionally, he recognises that he was the person who had to deal with the consequences of not getting treatment and support. Bongani acknowledges his differences and difficulties and seeks to be empowered by them.

Ekua's experiences of discrimination are explicit and such responses are dehumanising. Ekua's narrative exemplifies how such attitudes and the lack of awareness about HIV impacts on every aspect of his life including housing, leisure and health care.

**Ekua:**... *"One of the counsellors realised that we're using their studio for exercise and that we are HIV positive, she went and told...you have to sterilise the room because most of the people are HIV."*

*...My solicitor told the landlord that I'm HIV positive. The landlord went straight to court and terminated my tenancy agreement."*

He described his HIV status as creating a wall, *'...you announce that I'm HIV positive, you have just created a wall around yourself.'*

### Interpretative

For Ekua and Mehtab, this wall does not provide protection or safety, instead it is a divide that separates them from others. Ekua does not use the personal pronoun 'I' instead he uses 'you', possibly his way of creating distance from such stigmatising

attitudes and behaviours that are painful. These behaviours bring additional challenges and highlight the many ways in which the personal and social experiences of participants give the illness its meaning. HIV stigma, both enacted and felt not only shapes the way people with HIV are treated by others; it also impacts on the way in which people understand themselves and their identity following diagnosis.

#### **3.5.4 Summary.**

This theme has explored stigma related discrimination. It exists both within black African communities and the wider society and gives rise to a sense of powerlessness and isolation. An HIV identity appears to consume participants. They feel dehumanising and in order to protect themselves against stigma, participants hide their diagnosis as much as possible. Anything that could indicate they have HIV is concealed. There is a sense that these men present a false sense of self, one that is more socially acceptable. It makes their lives uncertain and challenging, as they never know how others around them will respond once their diagnosis is disclosed. Their world can be seen as fragile under these circumstances. Throughout this master theme the extracts reveal complex and difficult challenges which accompany an HIV diagnosis.

#### **3.6 Master theme three: Re-emergence of the self.**

The previous two themes have explored the challenges that participants were faced with in relation to HIV related stigma and the accompanied social isolation; leading on to an unwillingness or inability to access the support and resources that would help them to enhance their quality of life. During the times when they did access support, they were often faced with hostile and unhelpful attitudes from others. It was not surprising that participants felt that they needed to present an HIV free identity to reduce levels of social disapproval. Despite this, the participants eventually take steps towards revealing their HIV status to others and accessed resources. This was a significant turning point in the lives of men. Through the support of HIV organisations, they were able to find connection with others in similar situations.

### 3.6.1 Breaking the silence.

**Asante:** *"I spoke to a journalist, who bought me the air ticket to come over here. Journalists...He was living with me...he saw I was a bit uncomfortable then he started talking to me... So breaking this news and everything, empowered me, gave me the power to talk, to talk to other people."*

**Ekua:** *"It was a friend of mine, he suspected because of the way I was drinking, he could not understand why I was drinking. Then he told me that, 'you know for me, I'm HIV positive'. That's when I told him that, that's the same problem with me... He said, there are many organisations that can offer support and that's when he started to introduce me to organisations."*

**Dayo:** *"The doctor told me you can get support, there are organisations and you don't have to stay indoors that's when I started going to support groups."*

**Mehtab:** *"When I go to the doctor... is more information... they referred me to the group, a support group."*

**Bongani:** *"Like here, if I've got a problem... I just come here (HIV Support Service)."*

**George:** *"It would be helpful to talk about it, when you are first diagnosed, to help them understand that they shouldn't feel scared...like everybody was encouraging me."*

Participants felt more empowered, knowing that specialist support services were there to help them. 'Breaking the news', being encouraged by supportive others and having information about support groups seems pivotal in these men regaining a sense of self. The support that these men had needed was available to them. This helped to reduce their isolation they begin thinking about their diagnosis in a different light, so that they feel more in control. Actually taking the step to disclose their HIV status to friends or professionals away from a medical environment seems to be another life line for participants.

**Asante:** *"I'd retired from life on the first day that I heard about it...saying no, no, no...this is the end of my life...but like I am just like any other person in the world...I view myself as an ordinary person...a strong person...the difference is like just like the ocean..."*

**Ekua:** *" When I started accessing services, I have come to realise that I can still live. I have learnt a lot through associating with people... It has made a difference*



*because when you share experiences and problems, people can give you ways that you can overcome them."*

### Interpretative

Asante feels stronger through socialising and talking to others 'a *strong person*' there is a sense of renewed hope and vitality. '*The difference is just like the ocean,*' there is a sense that Asante has travelled a treacherous journey. The sea has many lives contained within it and this may be symbolic of the lives he has lived up to this point, a life that has been turbulent and unknown, much like the ocean.

For Ekua, meeting other people in similar situations helps him to realise that he can live with HIV without being isolated, through support organisations and group participant, they learnt more about the HIV condition. They saw for themselves others who were alive and well, they are able to seek encouragement that had previously been lacking. These participants had been starved of support and felt they were unable to reveal their HIV status away from medical professionals. Consequently some had developed unhelpful coping skills. Ekua had started drinking alcohol excessively. Mehtab was constantly worrying about other people finding out. Now these men had somewhere to go, life was being poured back into them, giving them hope that they could eventually begin integrating their HIV status into their identities, rather than seeing their status as an aspect of themselves that sidelined at every opportunity. They were able to foster a sense of safety amongst their peers in the support organisations where they experienced a sense of commonality and acceptance. Being away from their families, this peer support seems of particularly importance. For some of the participants, being in an HIV related environment has protected them from stigma related threats (Chanard, 2007).

Some participants begin to immerse themselves in support organisations and engage in beneficial activities to raise awareness of HIV. Here, their HIV status has taken a central position within their identity. Their HIV status is being embraced rather than rejected.

**Asante:** *"We talk...direct people to organisations and do partnerships with the NHS and other organisations."*

**Dayo:** *"I was doing some outreach work and we were doing some HIV testing."*

For others treatment and support has given them a new lease of life, unimaginable at the time of their diagnosis. Those participants now have a sense that they had regained some normality in their lives.

**Mehtab:** *"Yes I feel very good, I am happy, I busy, and I feel like any person now."*

**George:** *"Well I'm not complaining since I have been treated...We are lucky to be alive. I am living on borrowed time."*

**Bongani:** *"Whilst I am having treatment, I can go on with my life."*

**Dayo:** *"I got counselling, that's when I started accepting that I can live with this condition and that I live a normal life...provided I'm taking my medication."*

George and Bongani reflect on the fact that medication keep them alive, this may not have been available to them in Africa. George sees this as living on borrowed time and Bognani feels that *'life can go on.'* Counselling helped Dayo to begin accepting his diagnosis. All participants experienced purpose and fulfilment in life again.

One of the divergent themes that arose for some participants in relation to accessing support concerned their gender. Both Asante and Dayo expressed that women often get preferential services and amenities over men. This can leave men despondent and vulnerable.

**Asante:**...*"A man, we are meant to be pompous and proud, so they don't get much tested. Projects talk about households, it talks about women and children, they are vulnerable... but men they can be vulnerable too...so we find more women being diagnosed than men."*

**Dayo:** *"Women get tested when they are pregnant there is no specific opportunities to get tested for men."*

Participants were speaking of men's reluctance to get tested for HIV. There is an suggestion that this can contribute to the spread of HIV (Foreman, 1999). Ideas about masculinity and restrictive characteristics that are socially derived and assigned to men about successful masculinity compound this impediment (Courteney, 2002). These connotations seem to have been internalised by men and they go on to develop into defences against HIV testing. Additionally, support services are orientated towards the needs of women and children (Barker & Ricardo,

2005; Doyal, Anderson & Paparini, 2009). This can form an additional barrier to accessing services.

### **3.6.2 Intimacy is difficult - challenging the mythical stereotype.**

In relation to masculinity and men's identities, participants spoke of the changes that they made in relation to their intimate relationships.

**Asante:**... *"Changed a lot in my err, my sexual life as well. I'm not very sexually active now."*

**Bognani:**... *"but probably it was on my mind was, when you got that disease, you are not supposed to carry on having sex, unprotected sex every time. So you have to leave those things."*

**Mehtab:** *"I stopped completely."*

**George:** *"Well I have just had to stay away from having any sex."*

**Ekua:** *"I was not interested in sex, my sex life stopped, I had no interest in having a relationship."*

#### Interpretative

The diagnosis appears to have forced the men to consider their priorities. Living in accordance to the ideal of masculinity that is socially sanctioned was no longer considered to be relevant or appropriate for them. There is evidence of disapproval being shown towards men that continue to engage in risky sexual behaviours following the diagnosis. The majority of participants adopted behaviours that could be described as resisting the centrality of sexual prowess to hegemonic masculinity. Despite losing sexual partners and experiencing a decline in sexual performance and desire, they were in control of their intimate lives.

**George:**... *"Some people don't mind to carry on having sex. They think it's like revenge, if I have got it why can't he or she get it? I have heard of people spreading it all over and you know it's not nice, it's very very cruel."*

**Mehtab:** *"They should use protection, use condom, because you have to prevent HIV spread."*

#### Descriptive

It is evident that the men are reconstructing their masculinity, modifying social and personal responsibility to minimise the risks of infections to themselves and others.

These men had redefined their masculine identities as responsible and knowledgeable people, rejecting notions of hegemonic masculinity that could be harmful to them and others. Acquiring more information and knowledge about the disease empowered them to gain control over their lives and to further adjust to their diagnosis (Mfecane, 2008).

**Ekua:** *"At first I thought that maybe I will get a relationship with err, somebody that is the same status as me. But the more I knew about HIV, that's when I learnt that there was re-infection and different strains of HIV, so this stopped me from establishing a relationship with anyone."*

**George:** *"Those that are infected have to be careful with how they exercise their sex life and they have to tell their spouses or their partners and that's very important."*

Mehtab was single at the time of his diagnosis not being in a relationship was very difficult for him, especially because of the cultural pressures imposed upon him.

**Mehtab:**...*"And in the community, if you are not married, you are not with somebody, then there is something wrong with you...cos of my age and even my family would say, why 'are you not married?' You should get married... I tried to meet a lady in the same situation, but err it didn't work... It made me desperate...it felt hopeless."*

#### Interpretative

Mehtab described a sense of helplessness regarding his situation. HIV health care professionals helped him to think about ways that he could meet other people with the same status as himself. Specialist staff appear to play a key role in providing emotional support, as well as practical advice and guidance on matters that help people to integrate in society and form meaningful relationships with others. They provided space for people where hope and possibilities for the future could be fostered. These resources are significant in supporting individuals trying to find fulfilment in their lives. There was a sense that specialist staff had become surrogate family for participants.

**Mehtab:**... *"Then one day I asked the nurse, and she said, if you go on to a website for positive singles and you can find what you're looking for."*

The side effect of HIV medication can have a negative effect on sexual functioning directly impacting on how men view themselves. For Dayo this change is uncomfortable, difficult to manage and come to terms with.

**Dayo:** *"For me, with this medication, I had a problem with my erection. Sometimes you feel so embarrassed (slight laughter) For me I find it not easy, but my partner was telling me, you don't have to worry that this happens..."*

Dayo is able to share his concerns with his partner, it made it less difficult for him to manage.

### **3.6.3 Drawing support from the church.**

Specialist support services, peer and relationship support play a key part in helping participants come to terms with their diagnosis and to rebuild their lives to the extent they are purposeful and fulfilling once again. Some participants spoke of the crucial role that their faith provides for them. Faith can provide a sense of meaning, wellbeing and be a medium for keeping focus on the present reality. It protects men from morbidity, mental health challenges and unhelpful coping behaviours.

**George:** *"You can even wake up, but my doctor says that this is how the drugs operate. Sometimes you can wake up at night and you can see somebody by the window. But there's nobody there. At these times... I put my prayer...on my pillow, if I forget, then something happens. It's nothing really serious, it's just the drugs. All I know that God can do miracles, that's it. So I think we should just say ok then, I will pray even though I might not feel like it, it is important."*

**Bongani:** *"You know God is very good. It's only God who gives and takes, gives and takes."*

**Asante:** *"Err if I've got difficult feelings and worries I cope with them by praying. That's my first port, praying and secondly going to other congregations to meet other people and to talk to other people. For me I have um the church as a vehicle, where I meet other people and err pray for myself and my life."*

#### Interpretative

There is a sense that faith supports participants during difficult times. God symbolises a protective figure, taking care of things that these participants were unable to control, 'God can do miracles,' 'God gives and takes.' Asante describes the

*'church as a vehicle,'* something that transports him through life, helping him to overcome challenges with more ease.

#### **3.6.4 Summary.**

This theme has captured the point at which things began to change for participants following their decision to disclose their HIV status and seek support. There was a sense that this marked the emergence of their new, stronger identity, one that incorporated their HIV status. Participants had made decisions about their intimate lives and drawn on support from peers to establish connections and a sense of belonging. They talked about the positive coping mechanisms they engaged in and some made their HIV diagnosis a central part of their identity, raising HIV awareness and providing support to others.

#### **3.7 Master theme four: Fatherhood - a changing identity.**

Previous themes have detailed the process participants underwent to begin to accept and incorporate their HIV status as part of their identity. Although initially, this appeared to be a difficult process, participants showed resilience and an ability to engage in positive coping skills following social engagement with peers.

The present master theme encompasses the re-establishment of relationships with their partners and children. All participants migrated to the UK leaving their family. Their narratives describe disclosure decisions and the process of maintaining relationships with children. It reveals the difficulties and challenges men experienced because of their non-resident father and his HIV status. Eventually, some men were reunited with their partners and children in the UK. Nonetheless, their relationship had changed. The theme captures how participants worked towards re-establishing and maintaining a connection with their children both in the UK and Africa.

##### **3.7.1 Paternal HIV disclosure.**

Participants seem to be concerned about the welfare of their children and their own desire to disclose their HIV status. However, due to their immigration status, participants spent long periods of time away from their families.

**Bongani:** *"For thirteen years, I hadn't seen my family."*

**Asante:** *"I lived in this country for five years before they (wife and children) came over."*

**Ekua:** *"For five years I hardly had contact with my children."*

**Dayo:** *"When I got my papers, I went home and I told my children."*

During the time when, participants were coming to terms with their diagnosis, they had serious concerns about telling their family. Each expressed that telling their children was important to them. Despite this, there was a sense that participants had become estranged from their partners and children, living away from them for lengthy periods of time. The majority of participants informed their children of their HIV status as soon as they were able to.

**Bongani:** *"When I first phoned them, they were shocked...they saw a photo of me...they said, 'dad you are very healthy,' ...I don't need to put something under the carpet. Cos one day, you open the carpet, there is shock."*

**George:** *"...I didn't want my children to think that somebody done it to me... they should know that this is not witchcraft. Ever since I told them I feel relieved."*

**Dayo:** *"I had to concentrate on the boys...it was important for me to focus on them and make sure they went for a test."*

**Asante:** *"I spoke to them one by one... Because I needed to give them a life line again, to watch out... use protective equipment."*

### Interpretative

There was a sense that participants did not want to keep their diagnosis a secret. They wanted to offer their children an opportunity to learn about HIV and protect themselves from contracting it. This contrasts sharply to their own experiences in Africa of HIV, where it was not talked about or discussed. Participants wanted to ensure the welfare of their children *'I needed to give them a lifeline'* through disclosure and dispel myths about HIV *'they should know that this is not witchcraft'*. Their disclosure decisions may have been influenced by the support and information they received when engaging with specialist support services in the UK. Additionally, these participants had a lot of time to come to terms with their diagnosis before telling their children.

Ekua did not disclose his HIV status to his children, Ekua feels responsible for contracting HIV. There is a sense that he thinks that he has let his family down. His

shame prevented him from speaking to his children. He regrets not telling them and this may have caused a further divide in his relationship with his children.

**Ekua:**... *"I have never told them, my wife told them I had HIV through activities...I have never had the courage to tell them... Actually, I feel bad about that. I should have been the person to tell them."*

### Descriptive

Ekua's HIV test was taken without his consent and his wife was informed by his own brother. From the onset disclosure decisions had been taken out of his hands. It seems as though he had little choice as to when to tell his children. He was blamed for contracting HIV and this may have been used against him. In contrast the others were unsure of how they contracted the virus, some had been violently attacked in prison, they may be perceived as blameless victims.

Mehtab had not disclosed his HIV status to his child as she was too young. The thought of telling her one day was never far from his mind. How to tell her and when to disclose, were questions he frequently struggled with. He has decided to answer his daughter's questions as honestly as he can when the time comes.

**Mehtab:** *"This is yeah, a very, very difficult decision. Even I have attend many, many workshops on how to disclose. But I think ok let me see when the time comes. But my wife she says, well when our daughter is old enough, she will ask us about these tablets and then we start tell her."*

### Interpretative

Although the HIV diagnosis did not stop Mehtab from getting married and having a baby, he finds it very difficult to think about parental disclosure. He feels that he is constantly lying to others *'...because when you are HIV, all the time, you lie.'*

There was a sense that Mehtab worries about this. He is concerned that letting his daughter know will cause her pain but if he does not tell her, he will have to keep the diagnosis a secret from her too. *'If I don't tell her then there is secrecy, if you tell her, then there is so much pain.'*



The HIV diagnosis continues to be painful to accept for Mehtab and an HIV free identity is adopted at every given opportunity. The internal struggles continue for him and the decision of when to disclose his HIV status to his daughter remains a dilemma.

### **3.7.2 A Father's loss of authority.**

This sub-theme explores the adjustment to participants' roles as fathers. Their parenting roles in Africa meant that they had more rights to determine how their children were brought up as well as control over decision making. There is a sense that these men were the providers, disciplinarians and had authority within the family whilst in Africa. In the UK they are trying to re-establish traditional roles as providers and disciplinarians but they experience conflict as a result. The adjustment to new cultural norms, together with the HIV diagnosis, at times left fathers feeling powerless. Immigration had challenged the stability and continuity of traditional fathers' roles and also their identity (see section 1.5).

**Asante:**...*"Being a father back home, you can rule with an iron fist, here there are laws...so being a father in this country you lose all your rights on your children...I have lost that authority as a father."*

**Dayo:** *"You've got limits bringing up the children here in this country... even a neighbour has responsibility of the children, but here if you are a neighbour, you cannot say anything...back home, even somebody in the village can discipline your children. But here you can't say anything."*

**Ekua:** *"A father in this country, you cannot exercise your authority in relation to discipline. The way we discipline back home is different to."*

**Bongani:** *"Being a dad, it's a challenging job. The only thing that I have discovered is that if you are a father, you are head....I want this done in this way, this is to be done in that way."*

#### Interpretative

There is a sense that participants found it difficult to come to terms with their loss of authority in the UK. *'Ruling with an iron fist'* suggests fathers make decisions for children on what is acceptable and unacceptable. Children have less autonomy and firm discipline is maintained on the children. Their rights over their children seemed

to have been challenged here. They have been forced to re-evaluate their relationships with their children, particularly as having them in their lives is so important.

Asante seemed to be very concerned about this loss of authority, he felt that his children were becoming too '*radical*'- not playing by the book. However he worked steadily to create a bond with them '*I created that bond, I got into them bit by bit and now we are together as a family.*'

Participants still feels that the HIV diagnosis has impacted negatively on their relationships with their children.

**Asante:** "*Living as an HIV positive father...has taken one of my children away from me. The eldest thinks that everything has gone wrong because of me.*"

**Ekua:** "*The diagnosis diminished my authority...I lost all power as the head of the family. It still hurts me. My interaction with my children became different...I can no longer model their future, guide them. I lost the role of parent to guide them...I cannot talk to them about sex awareness...you are no longer the right person who should be lecturing us...you no longer qualify for that role.*"

Asante's and Ekua's children seem to blame them for contracting HIV and appear to have reduced their respect for their fathers. This worries participants as they do not want their children to be vulnerable.

**Bongani:** "*I want my daughter to learn from mistakes...*

**Asante:** "*...They (children) all the time text other people but they can't even text me. Losing that grip as an HIV positive father, I feel bad for my children because they might end up in deep trouble....in the beginning I used to get mails, facebook...now they've changed.*"

**Ekua:** "*I always tell them that whatever my circumstances are still know your status (HIV) and your partners status...before they would not go a week without calling me...now...there is a distance.*"

### Descriptive

The relationship with their children has changed significantly; this could be as a result of the HIV diagnosis. It could also be concerned with the fact that their children are getting older and becoming more independent. It is understandable that participants have concerns for the welfare of their children. However there are a number of factors that impact on the father-child relationship. These include cultural changes, the fact that participants were reunited with their children after a long period of time and their children seeking more autonomy.

Bongani left children in Africa and for him, technology helped greatly to reduce the distance between his children and him. This was in contrast to Asante, where he feels that technology means that his children have more privacy and could be vulnerable.

**Bongani:** *"I communicate with them all the time, through telephone, Skype, Whatsapp...we support each other very well."*

**Asante:**...*"I needed my family more because of my status and all these things. And to think or comprehend that I do not live with the family that was the worst, the worst thing in my life."*

**George:** *"Well my experience is a good experience and I like to be there and my children love me, they still love me... I'm very close with my children. Even though they are now grown up they are still my children."*

**Dayo:** *"They are supportive, they always ask me oh dad how are you doing?, how are you? How is the medication? Are you taking your medication? they are supportive."*

Mutual support between family members seems evident. Men maintain regular contact and provide support to partners/wives and children. They in return ensure the wellbeing of participants. This contact appears significant regardless of the fact that some men were non-resident fathers. From this perspective the HIV diagnosis seems to have brought the family closer together. However, illness variables, complexity of children migrating to the UK following their fathers' HIV diagnosis and cultural differences, should not be underestimated.

### **3.7.3 Summary.**

This theme has explored participants' adjustment to their roles as fathers. This process is immersed in anxieties about their children, having knowledge and understanding of the disease and being able to protect themselves. In some cases their HIV diagnosis had brought fathers closer to their children becoming a source of support. In other cases the diagnosis caused the parent-child relationship to weaken. Fathers were seen as being culpable for contracting HIV and were no longer respected by their children, despite attempts made by men to rebuild their relationship with their children. Culturally, the loss of respect and authority is difficult in relation to a collectivist culture where men have overarching responsibility and control over decisions. They have had to adjust to the level of independence and choice their children have in the UK. This can be a contributing factor for their anxieties about their children making decisions that could compromise their own health and wellbeing.

## CHAPTER FOUR:

### DISCUSSION

#### 4.1 Overview.

The study aimed to explore the impact and effects of an HIV diagnosis on black African fathers in the UK. This chapter discusses the results in light of the existing literature and psychological theory. As this study utilised Interpretative Phenomenological Analysis (IPA), unexpected themes were discovered and consequently some of the literature introduced is new (Smith, Flowers & Larkin, 2009). The clinical implications for the field of counselling psychology, methodological limitations as well as implications for further research are also discussed.

IPA was utilised to analyse interview transcripts for the main research question, '*what are the lived experiences of HIV positive black African fathers in the UK?*' The four master themes provided an overall account of what it is like for black African fathers living in the UK who are HIV positive.

The master themes were; responses to HIV diagnosis- *the demise of the physical and social self*; HIV stigma- *'they don't realise that anyone can get it'*; *'re-emergence of the self'* and *'fatherhood- a changing identity'*.

The following sections discuss stigmatising identity- internal struggles; community and social responses - external struggles; loss of Generativity; gaining control; reconstruction of masculine identity; re-establishing parenting roles; loss of authority.

#### 4.2 Stigmatising identity - internal struggles.

The first two themes encapsulated the significance of the disruption that an HIV diagnosis can have on participants that extends beyond the physical symptoms of the virus and quality of life. Participants placed emphasis on the social issues surrounding HIV, particularly HIV stigma. This was evident in the fact that participants only briefly mentioned the physical symptoms of AIDS they experienced when they initially became unwell.

Their initial response to the diagnosis was one of shock, the diagnosis had brought to the forefront of their minds experiences of trauma, narratives and explanations of

the ways in which people in Africa that were HIV positive were treated. These translocated men carried their identities with them as memories of their communities as well as their layers of trauma (Crossely, 2000). In a country where treatment and resources were scarce and health care systems had experienced severe decline amidst the economic and political disarray and poverty (Duffy, 2005), people dying of HIV/AIDS was a stark reality. Understandably, if these men had witnessed and experienced first-hand losses, fear that they would die in the same way too were very real to them (Flowers, Davis, Hart, Rosengarten, & Imrie, 2006). These memories of their communities were strong and reactivated by learning of their own diagnosis. Words such as *sephamola- a walking coffin* were commonly used to describe someone with HIV/AIDS this meant they were beaten by death (Dageid, Govender & Gordon, 2012). Additionally, those with HIV in Africa were viewed in a negative light, as HIV was associated with promiscuity and homosexuality (Goldin, 1994).

As previously mentioned, the emotional response was one of shock (Stolow, Atwood & Orange, 2002). Their HIV diagnosis could be situated and contextualised within the political persecution experienced by some participants. Such experiences were highly subjective, constructed with personal meanings of terror and disconnection (Herman, 1992, 1997). The men were unsure whether they could escape from persecution already they had experienced a threat to their lives. The diagnosis compounded this experience and persecution they endured in Africa shadowed by the very real threat to their lives.

There was a sense of powerlessness and defeat. These factors may have contributed to the incidents of late diagnosis often occurred within this population (Rice, Delpech, Sadler, Yin & Elford, 2013, Doyal, Anderson, Paparini, 2005, Low, Paine, Clark, Mahalingam, & Pozniak, 1996, O'Farrell, Lau, Yoganathan, Bradbeer, Griffin & Pozniak, 1995, Saul, Erwin, Bruce, Peters, 2000, Del Amo, Petruckevitch, Philips, Johnson, Stephenson et al, 1998,).

Some of the participants had been hurriedly forced to leave Africa and were alone when they received their diagnosis. Forced displacement in itself and resettlement in a new environment can cause physical as well as psychological scars. Migrants, who were weakened physically and/or psychologically by traumatic experiences,

underwent continuous stress regarding adaptation, acculturation and integration into a new society and were especially vulnerable to physical and mental illness. According to the Conservation of Resources Theory (COR) (Hobfoll, 1998), migration stress can be explained by the threat of loss and actual loss of resources of any kind. The chance to compensate these losses and to replace these resources can be very limited at least during the early stages of the adaptation process in a new country. This is inevitably associated with adapting to a different climate, new language, unfamiliar customs, cultural norms and values (Elford, Ibrahim, Anderson, Bukutu, 2008). Migration can mean the loss of status, survivor guilt at having left family behind and constant thoughts about duty of care for them (Graham & Khosravi, 1997). The loss of family support was evident; it had not been possible for participants to mobilize this traditional support and inevitably, this elevated their stress levels.

The actual mobilisation of support was significant, even when participants had family and other relatives near them, the social and biological implications of HIV created interpersonal conflict and short-circuited potential avenues of support (Vinokur, Schul, & Carplan, 1987) (Mehtab).

#### **4.2.1 Community and social responses - external struggles.**

Close knit communities are formed in order to maintain a shared identity comprising of cultural norms, values and beliefs. These may be heterogeneous in nature they share some homogeneity, such as shared commonalities of understanding human existence in relation to others with an emphasis on belonging and connectedness (Poindexter, Henrickson, Brown, Fouché & Scott, 2013). These communities are formed to develop a support structure for people. They come together to share common norms and values that are helpful to maintain their identities and connection to their heritage. Although these networks are cohesive, they are formed within a wider social context of political and social inequalities and with a diagnosis of HIV were excluded. This exclusion served to maintain the stability of communities by policing HIV disclosure to protect themselves from public criticism (Dodds, 2006). These participants may have reached a crisis point, post diagnosis. Gerhardt's (1989) 'crisis model' can facilitate the understanding of this. The model is primarily, but not exclusively associated with the consequences of labelling and stigma on

identity. The consequential onset of a chronic illness is seen to irreversibly change the social status of an individual. Immigration, to a foreign country meant that their social status had changed again. Adding to this a diagnosis of HIV meant a further change requiring adaptation. Four out of six participants had been diagnosed with HIV in the UK. Their withdrawal from the community and their deviation from cultural norms and practices may have been seen as 'deviancy' regardless of whether people in the community knew about their diagnosis or not. The social and cultural position of these men was fragmented by their HIV diagnosis. This fragmentation was highlighted in their narratives about being part of the black African community in the UK and having HIV (Flowers, Davis, Hart, Rosengarten & Imrie, 2006).

Here there was fear that HIV would bring with it chaos and ultimately fragment/destabilise an already fragile identity structure. This process of 'othering' produced feelings of comfort, security and a sense of personal invulnerability (see Clarke, 2008). Consequently participants with HIV become isolated and access to socio-emotional, financial and informational resources provided by such communities had diminished. The participants strived to pass as being HIV free as frequently as they could within their own communities to prevent themselves from becoming ostracised.

Winnicott, (1967, 1989) developed the concept of the true and false self. The true self is an authentic expression of a person's sense of self and the false self is developed as a defence against rejection. In relation to the participants, they had internalised societal standards and consequently the HIV part of them was believed to be bad. Levin (1971) noted that shame frequently caused a person to hide or avoid interpersonal contact as a protection against rejection. Here the purpose of the false self is to protect the true self from further traumatising; this only leads to shame and humiliation about hiding the true self. The participants seemed to be defined by their spoilt identity. Only one participant, Bongani, actively defended against this stigmatized identity (Tsarenko & Polonsky, 2011).

#### **4.2.2 Loss of Generativity.**

One polarity included in Erikson's (1982) psychosocial theory of identity development is that of Generativity versus Stagnation. This is the stage of development that is related to middle adulthood, and relevant to the men in this study. Middle adulthood



has been characterised as a time when people offset their fears of stagnation with expressions of generativity, which include participation in the wider society, caring for the family and being economically active. Failure to attain Generativity can lead to stagnation and personal impoverishment. Erikson elaborated on elements of stagnation by including 'Rejectivity'; this is the exclusion of individuals or groups of people from one's caring attention. This period is defined heavily by the roles people play within family and community structures (Sugarman, 2004). Rejectivity is the core pathology of stagnation, and this can occur against families, specific social groups as well as one's self. It is the vehicle of 'authoritarianism' (Erikson, 1982). Here, participants' ability to be generative was greatly limited due to their reticence to access services because of stigma. When they did access services, they were very concerned that others in the community would find out about their status. Therefore HIV stigma in many cases prevented men from accessing support earlier, resulting in varying degrees of stagnation.

#### **4.2.3 Summary.**

This theme explored the felt and enacted stigma that the majority of participants experienced within their communities and wider society. It explored the psychological impact of an HIV diagnosis and its impact on participants' daily lives. In order to protect themselves participants felt unable to disclose their HIV status. As a result their lives became very isolated because their HIV status had become the dominant identity (Goffman, 1963) and to protect themselves from rejection, they developed a false self (Winnicott, 1967).

#### **4.3 Gaining control.**

In the second master theme there was evidence that participants began to gain more control over their HIV status and made attempts to integrate their status into their identities. They did this by making selective disclosure decisions. Some participants chose to reveal their HIV statuses to family and friends (Ekua and Asante) while others (Mehtab, George and Dayo) took the advice of healthcare professionals to seek support from HIV support services.

Gerhardt's (1989) illness model focuses on negotiation, and the emergent nature of the chronic illness experience. This model emphasises adaptation rather than the adoption of a 'deviate identity' resulting from others' negative perceptions (McIntyre,

2006). In line with this model's emphasis on adaptation, within the present study, there were signs that participants had begun to embrace the change in their health status. HIV services and particularly support groups were central to aiding participants to reconstruct their identities.

Baumgartner & David (2009) and Tsarenko & Polonsky, (2009) also found that support groups played a pivotal role in helping people to integrate their HIV status into their identity and reduce social isolation. There was a sense that participants were immersing themselves in support organisations (Baumgartner, 2007) and engaged in generative activities to benefit the community, by raising awareness of HIV and promoting safer sex. Brashers, Haas, Klinge, & Neidig (2000) found that engagement in advocate and activist roles challenged feelings of helplessness and gave control and agency to the individual. Seeing themselves as active and as experts in their own experience empowered participants, so that the HIV diagnosis no longer had a master status (Goffman, 1963).

Participants had also been able to integrate their HIV status into their identities and carved for themselves a new sense of purpose, hope and agency. This resonates with Taylor's (1983) Cognitive Adaptation Model to threatening events. The men attributed this to support, the availability of medication and inner strength to make changes in their lives such as dietary and sexual practices. It gave them a sense of mastery and control over their lives, enabled them to develop adaptive coping skills and cultivate an appreciation for their life. A process of critical reflection (Mezirow, 1990) also appeared to have taken place. Men had re-evaluated their priorities. Participants expressed a greater need to be connected with their families and children (see section 3.7).

Spirituality and religion also provided participants with a source of strength. Many believed in the power of God as a major factor in maintaining future hope (Doyal, Anderson & Paparini, 2009). For some participants, religious beliefs also helped them to cope with uncontrollable thoughts, feelings and experiences. For example, George wrote a prayer before going to sleep, because he was experiencing hallucinations due to the side effect of his medication. Reading the prayer at night helped him to stay focussed and recognise that the hallucination was unreal (3.6.3).

#### **4.3.1 Re-evaluation of masculine identity.**

HIV support services and groups also play a resocialising role in terms of how masculinities are constructed and lived. They facilitate confidence in men allowing them to resist conforming to social expectations and restrictive notions of masculinity, leading on to more positive behaviour such as choosing to be more accountable.

Here evidence of positive change in men's lives emerged which contrasted with their initial responses to their HIV diagnosis. In relation to the Illness Representation Model (IRM) (Leventhal, Benyamim & Brownlee 1997), participants' beliefs about HIV meaning death had now changed. They could understand that medication had given them a new lease of life and the opportunity to re-establish and negotiate their intimate relationships.

Historical developments in different parts of Africa have shaped masculinity. This has been influenced by economic, social and cultural pressures on men to demonstrate masculinity through unsafe sexual practices (see Campbell, 2007; Hunter, 2005; Lindsay & Miescher, 2003; Morrell, 2001; Noone & Stephens, 2008; Reid & Walker, 2005; Simpson, 2005). Following a diagnosis of HIV, research suggests that high risk sexual behaviour is markedly low (Marks, Crepaz, Senterfitt, & Janssen, 2005). Participants spoke openly about the loss of interest in sex and expressed concern about passing HIV on to partners as a major constraint on their sexual activities (see section 3.6.2).

The men reconstructed their masculinity by elevating their social and personal responsibility to take care of themselves and others thereby minimising the risk of further infection. These men had redefined their masculine identities as responsible and knowledgeable and rejected notions of hegemonic masculinity that could be harmful to them and others. This is congruent with findings from Doyal, Anderson & Papparini (2005). This challenged the mythical stereotype of black African men spreading HIV (Caldwell, Caldwell & Quinn, 1989) (see section 1.4). Acquiring more information and knowledge about the disease meant that they gained control over their lives, helping them to further adjust to their diagnosis (Mfecane, 2008).

### **4.3.2 Summary.**

This section discussed the turning point that men experienced in relation to their HIV diagnosis. Participants talked about their illness and began to access social support in the form of support groups within specialist support services. This helped them greatly to incorporate their diagnosis into their self-identity. Support groups became safe places where men were able to explore their concerns without the worry of rejection. Some participants became advocates, promoting HIV awareness within their communities. Others found solace within these services, away from the negative responses and reactions of people within their own communities and wider society. Participants were able to foster helpful coping strategies and gain control over aspects of their lives such as relationships and intimacy. This counteracted the stereotypical notions of hegemonic masculinity and absent fathers.

### **4.4. Re-establishing parenting roles.**

Making disclosure decisions about their HIV status to family and particularly their children and the potential impact that this would have on their relationship with them was of concern to participants. Men reflected on their changed roles as fathers in the UK. The immigration process had meant that fathers had not played an active parenting role in the lives of their children for long periods of time. All men in this study expressed their desire to play an active role and made significant efforts to stay in contact with their children, especially the ones who remained in Africa. Some participants had been successfully reunited their families from Africa, in the UK (Asante, George, Ekua), however the HIV diagnosis had meant that the participants were no longer living with their partners and children (Ekua). Re-establishing the relationship with their children was considered important but proved to be challenging.

Men frequently expressed that they did not want to hide their HIV diagnosis from their children, only for it to come as a surprise and shock to them later. In relation to the Competing Consequences Theory of disclosure (Serovich, Lim & Mason, 2008), these men were primarily concerned about the welfare of their children. They wanted to make them aware of the disease and dispel commonly held myths about HIV, for example that it occurs through witchcraft (Rwemisisi, Wolff, Coutinho, Grosskurth, Whitworth, 2008) so that they could protect themselves from the disease later on in

their lives. Their children were old enough to understand what it meant for their fathers to have HIV. This research support the findings of Letterney, (2012), which concluded that fathers were likely to disclose to older children and that it was an important step in future care planning.

Given the difficulties with black men testing for HIV, Dayo had encouraged his sons to get tested for HIV. He emphasised the important role men/fathers play to ensure that the next generation was aware of HIV risks and the importance of testing.

In contrast, Ekua had not disclosed his HIV status to his children. Ekua felt culpable for contracting the disease, feeling shame and guilt for having let his family down. The diagnosis had furthermore fragmented his family; it had led to the break-up of his relationship with his wife and distanced his relationship with his children (Doyle, Anderson & Paparini, 2005). Not telling his children had caused him further anguish and regret. This is just one example of the way in which an HIV diagnosis can be a very isolating and lonely experience for those trying to come to terms with it. The self stigma and blame can mean that isolation appears at the time to be the only option. This is an example of the way in which the diagnosis can change the positioning of men within their family structure (Doyle, Anderson & Paparini, 2005).

#### **4.4.1 Loss of authority.**

Fathers who had traditionally adopted an authoritarian parenting style (Baumrind, 1971) found themselves renegotiating this in light of cultural and legal changes in the host country. All men had contact with their children and their concern was for their children's welfare, to ensure that they knew about HIV, so that they could protect themselves. Their parenting role when living in Africa had included the right to determine how their children were brought up as well as having control over decision making. There was a sense that these men were the providers, disciplinarians and had authority within the family. Some of this authority had been lost for multiple reasons, moving to a host country (Arnold, 1999) where legislation and child rearing practices were different. Fathers were trying to maintain traditional roles as providers and disciplinarians (Jabeen & Karkara, 2005; Doyle, Anderson & Paparini, 2005) but they experienced conflict as a result. The disconnection from their families seemed noteworthy, on coming together with their family their traditional system needed re-evaluating. The adjustment to new cultural norms, together with the HIV diagnosis at

times left fathers feeling powerless. Forced immigration had challenged the stability and continuity of fathers' roles and their identity (Bourgois, 1998; Dettlaff & Rycraft, 2006; Suárez-Orozco & Suárez-Orozco, 2009). There were multiple changes to hegemonic masculinity and fatherhood to adjust to. Their children may have adjusted more readily to the host culture, undermining the father's status and the family stability (Suárez-Orozco & Suárez-Orozco, 2009).

Relationships between parents and their children inevitably changed over time, as children grew up and become more independent, the men expressed their anxieties about this process. Their main priority was to safeguard their children from HIV infection. Talking to them and giving them guidance was important to them. The role of being a father was taken seriously and they wanted to do as much as they could to offer guidance and support to their children. Through their own journey of adjustment they felt able and in a position to provide this to their children. The commonly held beliefs about fathers playing an inactive role in the upbringing and welfare of their children (Datta, 2007) was not apparent in this research. The differences in lifestyle in the UK could be a factor; there are more opportunities for fathers to play an active role in the lives of their children, in contrast to Africa.

#### **4.4.2 Summary.**

Adjustment to their HIV diagnosis in relation to their roles as fathers is immersed in anxieties about their children having knowledge and understanding of the disease and being able to protect themselves. In some cases their HIV diagnosis had brought fathers closer to their children and they were a source of support. In other cases the diagnosis caused the parent-child relationship to weaken. Fathers were seen as being culpable for contracting HIV and no longer respected by their children despite attempts made by men to rebuild their relationship with their children. Culturally, the loss of respect and authority is difficult to deal with, especially in relation to their collectivist culture where men have overarching responsibility and control over decisions. They had to adjust to the level of independence and choice their children have in the UK. This could be a contributing factor for their anxieties about their children making decisions that could compromise their own health and wellbeing.

### **5.1 Implications for counselling psychologists.**

The present study utilised a small sample of six black African HIV positive men living in the UK with parenting responsibilities. Due to the small sample size, the findings of this research cannot be generalised. Nonetheless, this research is able to offer insight into the implications of working with this population, thus offering theoretical transferability (Smith, Flowers & Larkin, 2009).

This study contributes towards improving our understanding of the unique phenomenon of being a black African HIV positive father in the UK. It has focussed exclusively on men, their roles as fathers and the impact that a diagnosis had on their lived experience. Direct quotes have been presented to illustrate their narratives and substantiate results.

Given the histories of participants in this study, it is evident that a range of biopsychosocial factors interact and contribute towards their overall lived experience: forced migration, political persecution, violence, family loss, sexual exploitation and adaption to an unfamiliar culture, post-migration. The interpretation of their unique challenges and concerns could be oversimplified when addressing emotional and mental health issues for this group. Practitioners need to be mindful of this (Vostanis, 2014). Interventions delivered need to take into account cultural context and the unique ways that black African men make sense of their illness against the backdrop of past experiences and present concerns.

Therefore the findings of this study are useful to formulate difficulties that black African men may face in light of discrimination, HIV related stigma, masculinity and fatherhood. Providing a non-judgemental, a supportive environment to explore difficulties and challenges is therefore significant. This would help individuals to regain control and autonomy where the diagnosis, past traumas and current experiences may be causing disruptions and diminished sense of self. Here practitioners will be required to take a pluralistic stance (Cooper & McLeod, 2007), taking into account social context and anti-discriminatory practice (BPS, 2005).

Tait, (2013) recommended HIV Self-management programmes specifically for black African HIV positive women. Her recommendation was also relevant to black African men and could be helpful in addressing their diverse and unique experiences. For

example thinking about and coping with, the physical symptoms of HIV, medication management, communication with family and friends as well as health professionals. exploring the impact of stigma and issues of disclosure. Such an intervention could aid clients to come to terms with their illness and associated challenges.

Some participants expressed that one to one counselling was not accessed, however, they gained support from shared group experiences; this was akin to a sense of community and belonging that was fostered by participants (Dodds, Keogh, Chime, Haruperi, Nabulya, Sseruma & Weatherburn, 2004). Storytelling and folktales have significance in African cultures and thus, there may be value in establishing group counselling/therapy programmes focussed on the narratives (White, 2004) of men. These might help them to explore HIV in a relational context exploring illness and coping narratives (Kleinman, 1988). This would be a more therapeutic environment for counselling psychologists to work in, supporting men come to terms with and adapt to changes and challenges. Therefore such interventions should be considered within existing service structures.

Provisions to help men break social isolation and access activities such as social and leisure facilities would also help to foster their interests and cope with some of the physical symptoms of HIV and the side effects of prescribed medication.

Participants in this study expressed anxieties about the future, their role within their family, their future health and concerns about disclosure. The diagnosis was in the forefront of their minds and caused varying degrees of anxiety. Mindfulness based techniques delivered as part of a group therapy programme or psycho-education programme would also be beneficial as a strategy for coping with current anxieties (Palbom & Wilson, 2012). This could be delivered as part of an overall, broader programme, consisting of self- management and counselling groups.

Findings relating to the men's experiences of healthcare settings indicate that anti-discrimination training is required for health care professionals. Counselling psychologists could deliver workshops and training to health professionals as well as other community staff in order to raise awareness of HIV and its routes of transmission. They should also work towards establishing anti-discriminatory practice.



## **5.2 Research implications.**

The present study has explored the lived experience of six participants and forms one of the handful of studies that have explored the lived experiences of black African heterosexual men and women living with HIV in the UK (Dodds, Anderson, Paparini, 2005; Treisman et al, 2013; Tait, 2013, Flowers, Smith et al, 2009). The study was unique in that additionally it focused on the lived experience of men with parenting responsibilities in the UK. The majority of men had been diagnosed with HIV after they had children and had experienced forced migration. Some had been reunited with their children in this country, while other participants developed long distance relationships with their children.

Research in this area would benefit from future studies exploring men's decisions to have children following a diagnosis of HIV. Such research would contribute to developing our understanding of their decision making processes. This may provide greater insight into the type of support that would be helpful to men when making such life changing decisions or their concerns and worries about the support process. This type of study would also build on Sherr's (2010) research.

The present study only focused on men's lived experience of fatherhood. The lived experiences of HIV positive black African mothers would give the field of counseling psychology an understanding of this phenomenon and their unique experiences. Research could explore the mother-child relationship and disclosure decisions of HIV positive black African mothers living in the UK. This would build upon research by Triesman et al (2013), which explored the experiences of women who had learnt of their HIV diagnosis during pregnancy.

Although a number of studies into HIV disclosure have taken place (see section 1.6), a longitudinal study documenting the decision making process and disclosure of parental HIV would contribute to the present literature on disclosure (Qiao, Li & Stanton, 2013).

The advances in HIV medication means that there is now an aging population living with HIV (Lawence & Cross, 2013). Exploring the needs of older black African adults and their sense of self, having aged with HIV would be helpful to determine their

experiences and how service provisions needs to be tailored to meet their needs. Such studies could utilise a mixed methods approach and use psychometric measures to investigate variables such as coping, illness perceptions and stigma.

### **5.3 Critique of the research.**

The use of qualitative research makes a valuable contribution to the evidence base. This is because participants are able to explore issues pertinent to them. They are not constrained by narrowly focussed, conceptualised questions set out on a questionnaire (Dovey-Pearce, Doherty, & May, 2007). IPA is an ideographic approach that takes a personal focus to develop understanding of a particular phenomenon. It is unable to provide definitive or positivist answers. As this study utilised small purposive samples, it was not possible to make generalisations extending to the wider population. Although attempts were made to ensure the rigorous and transparent analysis of transcripts, it is the researcher's interpretation that it finally offered. Other researcher's may have given prominence to other features of the research.

However some salient themes of participants' experiences in this study may be transferable to future studies and could be used to develop further research. All participants were recruited via HIV support services, those that were not accessing services may have had a different experience (Walch, Roetzer, & Minnett, 2006). It is also acknowledged that the term 'African' has been used, this implies homogeneity within a diverse heterogeneous group of individuals.

The study involved individual interviews with participants. They gave the researcher an understanding of how masculine identities were performed in relation a female researcher. The researcher was able to identify the changes men underwent to redefine their identities in light of their HIV diagnosis. Consequently men spoke of the challenges and changes to their intimate relationships, the challenges of being fathers and powerlessness they experienced in relation to stigma and discrimination. If focus groups had been conducted, with participants, they would have had the opportunity to gain an understanding of how masculine identities were performed not only in relation to a female researcher, but also other male participants (Datta, 2007).

The participants in this study spoke English as their second language. Given that language is used to interpret and communicate meaning (Shineborne, 2011), if interviews had been conducted in their first language, they may have yielded different findings and possibly richer data (Tait, 2013). Nonetheless, every effort was made to ensure the trustworthiness and transferability of findings (Guba, 1981) (see appendix L).

It is also possible that attendance to support groups and engagement in support services may have influenced participants' answers to research questions in a positive direction. The present study found that support services and groups played a pivotal role, helping participants to begin integrating their HIV diagnosis into their identities. Finally, in relation to their parenting responsibilities, some participants may have given socially desirable responses, given that the focus of the interview was on their parenting roles (Lewis-Beck, Bryman & Liao, 2003).

## CONCLUSIONS

The present study provides a unique contribution to the under researched area of black African men living with HIV in relation to their role as fathers. Although Doyal, Anderson and Paparini (2005) explored the different constructions of masculine identities and how they impacted on the illness, experience with black African men is limited. The paradoxes of parenthood were discussed and their study found that men had a desire to have an active role in the lives of their children. This was not always possible because the diagnosis of HIV often separated families and the subsequent loss of authority and control was deeply felt. This was also found to be of significance in this current study. In contrast to other findings, this study did not find that men were worried about the consequences of their death and who would look after their children. Rather participants expressed that they wished to protect their children from HIV and offer support and guidance where ever possible, even when children seemed reluctant to want their fathers to play an active role in their lives. This difference may be due to the disparity in ages of the participants' children between the two studies.

Stigma played an active role in the lives of participants in this study and they felt that their authority as fathers was particularly undermined by their diagnosis. Support groups and HIV specialist services provided the most supportive environment for these men as well as close family members. They felt strongly that, within their community and within wider society, responses and reactions towards their health condition were unhelpful. This may have contributed to some participants developing a false self, an identity that was free of HIV when they interacted in the community, in order to prevent backlash. In contrast, other participants had immersed themselves into HIV related activities. This helped them to foster a greater sense of self that helped to fend off any potential identity threats. Participants had to renegotiate their identities as men, fathers, black African and HIV positive during their interactions with the wider society, their communities and family systems. This appeared to be on an ongoing process of adapting (Charmaz, 1995) and adjusting to situations. Although participants had developed positive coping strategies, their HIV status was never too far from their minds, shaping and colouring their daily lives. The men showed great strength and resilience in the light of their diagnosis and their

desire to go on living fulfilling lives, growing from their experiences and being grateful for the opportunity to acquire HIV medication.

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## **Appendix A - Research information sheet**

Jenika Patel Trainee Counselling Psychologist, Wolverhampton University,  
Wolverhampton

### **Thank you for considering taking part in this research project.**

This information sheet provides details about the research in order to help you understand what it is about, why it is being conducted and what your involvement will be. This information will help you to make an informed decision about whether you would like to participate in this research project.

What you need to know.....

#### **The Purpose of the Study**

The purpose of this study will be to explore the experiences of fathers who are living with the long term health condition, HIV. The aim of the research is to gain a better understanding of some of the needs of fathers and how these can be better met by health care professionals.

#### **Your role of participation**

Your role in this study is to tell your story of what it means for you to live with HIV and how it impacts on your role as a parent. In order to assist you in this, you will be requested to take part in an interview, guided by a number of semi-structured questions. The interview will be recorded and will last approximately 1 -2 hours and will take place at a previously agreed setting at a time of your convenience. Prior to the interview you will be asked to fill in a demographic questionnaire, which should take no longer than 10 minutes. The purpose of the questionnaire is to provide us with some background information about the participants who have been interviewed. You have the right to choose not to answer any of the questions asked in the questionnaire or during the interview process. You may also withdraw from the research at any point before the completion of the research report if you wish to do so. Following the interview, you will be given the opportunity to talk about how it felt to take part in the interview. This will take up to 20 minutes. You will therefore need to allow yourself approximately two and a half hours for the whole interview process. The interview will then be typed up to form a transcription of the interview. You will not be identified by name on either the tape or the transcription.

#### **Issues of anonymity**

The content of the interview will remain entirely anonymous. Any information about you will have your name and any identifying details removed so that you cannot be recognised. You can also request any information to be erased from the tape should you prefer it not to be included.

The interview will be exploring your life experiences, some of which may be unpleasant or difficult to remember. At the end of the interview you will be given the opportunity to explore your experience of the interview and to address any issues that may arise and could possibly have been upsetting or that may have taken you by surprise. A resource list has also been prepared for you to take away. This list will provide you with useful numbers of support organisations, counselling opportunities and telephone help-lines.

### **The benefits of taking part in the interview**

Taking part in this study may offer you the opportunity to find new meaning and insight into being a parent with HIV. Although your participation in this research does not guarantee this, it will allow you the opportunity to add to the growing field of HIV research aimed at helping improve therapeutic approaches and care.

### **The results of the research study**

The results of this study may be published in a professional journal but you will not be identified by name in any publication. You will be informed about the results of the study when it is finished.

### **Who has reviewed this study**

This study has been given ethical approval by Wolverhampton University. Approval guarantees that the project is not expected to involve any risk of harm greater than those involved in daily life. Approval also means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits, and that you have been given sufficient information to make an informed decision.

### **How do I take part?**

Once you have read this information, you will be given at least 24 hours to consider whether you would like to take part. I will then contact you by phone. Should you choose to take part, I will then arrange a time and a place for the interview. You will also be requested to sign a consent form to agree to take part in the research project, in addition to providing consent to the recording of the interview.

### **Support/ further information following the interview**

Following the interview you will be given a resource pack detailing names of various support groups, counselling opportunities and telephone help-lines. This has been prepared for you in advance in case you experience any distressing feelings and need someone to talk to.

Many thanks for taking the time to read this participant information sheet

Project Supervised by Dr Victoria Galbraith, Counselling Psychologist and Senior Lecturer Tel: Email: V.Galbraith@wlv.ac.uk or The Department of Psychology, School of Health and Wellbeing, Wolverhampton University, City Campus North, Nursery Street, Wolverhampton, WV1 1AD.



## **Are you a Black African father living with HIV?**

**If so, I would really value hearing about your  
experiences of being a father and living with HIV**

**The aim of the study is to understand more about the  
impact that HIV has on your role as a parent**

**By taking part in a friendly and informal interview, you  
will be able have your voice heard and contribute  
towards a better understanding of how Black African  
fathers can be supported**

**If you would like to take part in telling your story and to contribute  
towards some valuable research, please contact:**

**(Organisation details placed here)**

**You will be given a grocery store voucher to say thank you for  
your participation and local travel costs will be reimbursed**

**This research is being supervised by Dr Victoria Galbraith, Counselling Psychologist & Senior  
Lecturer in Psychology**

**Email: V.Galbraith@wlv.ac.uk**

**Appendix C-** Demographic table for participants (some information has been removed for confidentiality purposes)

<b>Participant pseudonyms</b>	<b>George</b>	<b>Asante</b>	<b>Bongani</b>	<b>Dayo</b>	<b>Mehtab</b>	<b>Ekua</b>
<b>Relationship status</b>	Married (Wife in the UK)	Married (Wife in the UK)	Married (Wife in Africa)	Married (Wife in Africa)	Married (Wife in the UK)	Divorced (Ex-wife in the UK)
<b>HIV status of partner</b>	Not known	Not HIV positive	HIV positive	HIV positive	HIV positive	Not HIV positive
<b>Number of Children in the UK</b>	One	Five	Three	None	One	Five
<b>Number of children in Africa</b>	Five	None	Two	Six	None	None
<b>Domestic arrangements</b>	Living with daughter	Living with wife and one child	Living in shared accommodation	Living alone	Living with wife and child	Living alone
<b>Length of time in the UK (years)</b>	9	13	14	13	10	19
<b>Length of time since diagnosis (years)</b>	10	13	14	11	20	20
<b>Immigration Status</b>	Asylum Seeker	Refugee	Indefinite Leave to Remain	Asylum Seeker	Asylum Seeker	Indefinite Leave to Remain
<b>Reason for coming to the UK from Africa</b>	Due to political unrest	Due to political unrest	Due to political unrest	Due to political unrest	Due to political unrest	Study and work
<b>Faith/Religion</b>	Christian	Christian	Christian	Christian	Muslim	Christian
<b>Education levels</b>	Not known	University Degree	Not known	Not known	Secondary School	University Degree
<b>Employment status</b>	Unemployed	Employed	Employed	Unemployed	Unemployed	Unemployed



## Appendix D - Interview schedule

### Interview questions

#### INTERVIEW SCHEDULE

**Introduction to the interview:** I am interested in finding out about your experiences of being diagnosed with HIV and how this may impact on your parenting role. I am going to ask you a number of questions to help guide this process. Please talk openly and honestly about your experiences, but do not feel that you have to talk about anything that you are not comfortable about.

#### Description of diagnosis & impact on life

##### **1/ Can you tell me about how you came to find out that you had HIV?**

*Prompts: Who told you? Where were you? How did you feel at the time?  
What did you do? What was your biggest worry? What treatment options were you given? Which services were you told about?  
Where you able to speak to anyone about it?*

##### **2/ What does having HIV mean to you?**

*Prompts: How you view yourself  
How you think others view you  
Spirituality  
Religion  
Work life  
Asylum status (if applicable)  
Support systems  
Relationships  
Is there a difference between how you were feeling when you were first diagnosed and how you feel now? If the meaning of HIV has changed, what facilitated this change?*

##### **3/ What did having HIV mean to you prior to your diagnosis?**

*Prompt: What did you think about HIV prior to hearing your status? What image did you have of people having HIV or how would you have described HIV to others? What did you believe that the consequences of the illness would be? What ideas did you have*

*about the causes of HIV? If your family/friends know what has their reaction been, if any, to your diagnosis?*

**4/ In what ways have you made changes in your live, to adjust to living with HIV?**

*Prompts: How did you feel about the different treatment options given to you?*

**5/ In What ways, if any, has been a man influenced your experience of living with HIV?**

**6/ When you have difficult feelings or worries how do you try to cope with them?**

*Prompt: What do you do?*

*Internal/ external coping mechanisms/ cope alone/ with others/ avoidance/active coping*

Parenting

**7/ Can you tell me about your experiences of being a father?**

*Prompt: What was it like to be a father in your home country?*

*How is this different to your experiences of being a father in this country?*

**8/ In what ways do you feel that being diagnosed with HIV has made a difference to being a father?**

*Prompt: Your interactions with your children*

*Your relationship with them*

*What you think about in terms of their future and yours*

**9/ Are they aware of your diagnosis?**

*Prompts: If no, what sorts of things stop you from telling them?*

*If yes, how did they respond?*

**10/ How are you currently feeling about the decision you have made regarding disclosure to your children?**

*Prompt: Do you think that it was the right decision? Tell me more How has this impacted on your relationship with your child/children?*

**11/ What thoughts and feelings do you have of getting your children tested for HIV? (If applicable)**

Summarising questions

**I am interested in the knowledge people with HIV can pass on to others. What would you say to children and their parents who are infected or affected by HIV?**

Prompt: What do you know now that you would have liked to have known yourself as a recently diagnosed person?

**Do you feel that society knows enough about HIV? If you could promote one message about HIV in society, what would it be?**

**Is there anything else that you would like to add about your experiences of living with HIV and being a father?**

Ending the interview

Thank you for participating in the interview process. Is there anything you would like to be erased from the tape that you still wish to be included in the study? Would you like to add anything to what you have talked about today? Do you have any questions you would like to ask me?

## Appendix E - Consent form

### Consent Form

**Researcher:** Jenika Patel, Doctoral Trainee Counselling Psychologist  
**Research Supervisor:** Dr Victoria Galbraith  
**Address:** The Department of Psychology, School of Health and Wellbeing,  
Wolverhampton University, Wolverhampton,  
Tel: 01902 323599

Firstly, thank you for agreeing to participate in the following research project entitled The Lived Experiences of Black African HIV positive fathers.

The aim of this form is to outline the purpose of the study, as well as to gain your consent for participation. The purpose of the study is to gain insight into the experiences of fathers living with HIV.

The method I will use to collect information is interviews lasting approximately 1 hour. You are encouraged to ask any questions at any time about the nature of the study and the methods used. Your suggestions and concerns are important to me.

I guarantee that the following conditions will be met:

Please tick

I understand that the research will be conducted according to the Code and Conduct and Ethical Principles of the British Psychological Society.	
I understand that the results of this research will be coded in such a manner that my identity will not be attached to the information. The key that lists the identity and code number of the participant will be kept securely in a locked file, separate from the research data, and will be destroyed after two years of the study.	
I understand that the results of this research may be published in a psychological journal or otherwise reported to scientific bodies. However, the participant will not be identified in any publication or report.	
My participation is voluntary. I am free to withdraw consent and discontinue participation before interviews are transcribed.	
This project is not expected to involve any risk of harm greater than those involved in daily life, and all possible safeguards will be taken to minimise potential risks.	

Print Name (Block Capital Letters).....  
Signature.....  
Researcher's Signature.....  
Date.....

## Appendix F - Demographic form

### Demographic Form

In order to help me with this research, I would like appreciate it if you would fill in this questionnaire which requests some background information about you. The information that you give in this questionnaire is confidential, this means that it will not identify you in any way. Please feel free to miss out any questions that you do not wish to answer.

1. How old are you?

-----

2. What is your gender?

-----

Male ☐ Female ☐ Other ☐

3. What is your country of origin?

-----

4. If any, what tribal group do you identify with?

-----

5. How would you describe your ethnic origin?

-----

6. What is your immigration status?

-----

7. Is English your first language? Yes ☐ No ☐

If no, which language is your native language?

-----

8. How long have you lived in the UK?

Years\_\_\_\_\_Months\_\_\_\_\_

What brought you to the UK?

-----

9. What is your highest educational qualification?

None ☐

Degree ☐

School level ☐

Post graduate studies ☐

Diploma ☐

Other, please specify-----

10. Are you employed?    Yes    ☐                      No    ☐

If yes, what work do you do?

-----

11. Which religion or faith do you most closely identify yourself with?

-----

12. What is your current partnership status?

Single ☐                      In a relationship (living together) ☐

Married ☐                      In a relationship (not living together) ☐

Separated ☐                      Divorced ☐

Widow ☐

Did/do they have HIV?                      Yes ☐                      No ☐

13. Do you live alone?                      Yes ☐                      No ☐

If no, who do you live with?

-----

14. How many children do you have?

-----

15. What are their ages?

-----

16. What are their genders?

-----

17. When were you first diagnosed with HIV?

Years\_\_\_\_\_Months\_\_\_\_\_

18. Are you currently taking any anti HIV drugs?

Yes ☐

No ☐

If Yes, how many\_\_\_\_\_ Date/s when started\_\_\_\_\_

19. How well do you feel supported in you HIV management?

Very well ☐

Quite well ☐

Fairly well ☐

Not so well ☐

Not at all well ☐

20. If you do feel supported, how is this support given, i.e. where and who from?

-----  
-----  
-----  
-----

Thank you for your cooperation

## **Appendix G** - Duration of interviews

<b>Participant's Name</b>	<b>Duration of interview</b>
Asante	1 hr 6mins
Bogani	1 hour 13mins
Dayo	40 mins
Ekua	50 mins
Mehtab	52 mins
George	41 mins



## **Appendix H - Two excerpts from researcher's reflective diary**

### **Interview 1**

I have completed my first interview and I recognised that I felt apprehensive yet excited about meeting the participant and hearing his story. I wondered how I would be received by him and what he would make of me and therefore I recollected that I waited in quiet anticipation, making sure that I had everything I needed. I was shown to a small, comfortable room, with two sofa chairs in it, the lighting was good and the room was airy. I took a seat in one of the chairs and checked that my body posture was open, relaxed and comfortable so that any signs of apprehension were not visible.

I left the room to familiarise myself with the kitchen so that I could make a hot drink for the participant when he arrived. As I did this I met staff and service users alike, they were welcoming and friendly and this put me at ease.

Soon after a gentle man walked into the room, he introduced himself to me and I shook his hand. I noticed the look of solitude and wisdom etched on his face as I went to make him a cup of coffee. When I entered the room, he was sat comfortably in his chair and I asked him where he would like my Dictorphone placed. I wanted to ensure from the onset that the interview process was lead by him and that his needs were being taken in to account. We went through the research information sheet, he signed the confidentiality waiver and together we completed the demographic form.

As the interview commenced, I could sense that words did not come easy for him. Talking about painful experiences and his journey to the UK was difficult. He was given time and space and I probed little, sensing that he would tell me what he wanted to, in his own time. Although he had had difficult past experiences, he spoke of his gratitude for being alive, even though he recognised his own dependence on his children at this time. He has told very few people about his HIV diagnosis and he sought solace in faith and his art. He was a private man, who spoke little to other community members. I was grateful that he had taken the time to speak to me. He had bought with him some of his art work to show me, it was spectacular! I felt very privileged, that he had agreed to be interviewed.

#### **Interview 4**

I had walked into a building that was looking dated and worn. As I entered the multi storey building, there were stairs taking me to the rooms where the HIV service was housed. The corridors were dimly lit and crowded with objects. It felt like I was the only person in the building. As I knocked on the door, someone came my way and asked me to take a seat in the corridor as no one from the service had arrived yet. It was a warm sunny day and the corridor was very narrow. Soon after the lead professional of the HIV charity arrived and we went in to a room, which was cluttered and crowded. The charity had recently relocated and I could sense that funding cuts and limited resources had had an impact on this organisation. I was led into a small office and this is where I carried was to carry out my interviews. I had taken with me a variety of Indian snacks for people. As they came in, they were friendly and talkative. The snacks were received well, as they began telling me about their experiences with Indians, some of whom were their neighbours in Africa. Between the participants and I, this helped to build a rapport and this helped me to feel more relaxed too.

The interviewee was articulate, enthusiastic and inquisitive about how my interest in HIV arouse, as I spoke about my placement experiences and as the interview commenced I could see that this man was carrying a lot of guilt, shame and regret. His HIV diagnosis had cost him a lot , including his relationship with his wife and children. He has been through a hard time, with alcoholism, isolation and low mood and he had steadily worked hard to rebuild his life after years of feeling hopeless and helpless about his situation. He had formed linked with other people in a similar position as himself and he drew a lot of strength from them. The pain and difficulties he has with his children, the loss of his role as a father was evident and as he spoke about his experiences tears welled in his eyes. The discrimination and prejudice he spoke about added to his distress and this was something that he, along with others diagnosed with HIV seem to have to cope with on a regular basis. The social realities and difficulties that people face seem so far behind the medical advances that have helped define HIV as a long term health condition. Advances in science has meant that people living with HIV have a body that functions well, however socially it remains a debilitating disease impacting on a person's quality of life.

## Appendix I - Coding for Asante's transcript

Emergent Themes	Original Transcript	Exploratory Comments
<p>ill</p> <p>Arrival to the UK</p> <p>Disorientation</p> <p>Shock</p> <p>Excessive thinking</p> <p>Fear</p> <p>Experiencing physical symptoms of AIDS</p> <p>Living with HIV</p> <p>End of life</p> <p>Loss of self/depression</p> <p>Questioning survival</p> <p>Lack of support</p> <p>Alone</p> <p>Loss of hope</p> <p>Isolation</p> <p>Trauma</p> <p>Persecution in Africa</p> <p>Fear of the unknown</p> <p>End of life</p> <p>Lack of support\HIV in Africa</p> <p>Being left to die</p> <p>HIV is overwhelming</p> <p>Foreign land</p> <p>(Navigating a new terrain)</p> <p>Lack of family support system</p>	<p><b>Interviewer:</b> Ok I'll just leave it here. (Dictaphone). OK, Asante the first question then is, can you tell me about how you came to find out that you had HIV?</p> <p><b>Asante:</b> Basically it was when I felt ill, in [REDACTED] in [REDACTED]</p> <p><b>Interviewer:</b> yes</p> <p><b>Asante:</b> I went to [REDACTED] in err, in [REDACTED],</p> <p><b>Interviewer:</b> OK</p> <p><b>Asante:</b> In [REDACTED] because of err, I lived in [REDACTED], then, that's where they err did the bloods and everything. Then I learnt that I was HIV positive.</p> <p><b>Interviewer:</b> And when was that?</p> <p><b>Asante:</b> Yes it was, <u>soon after coming into the country</u>, when I err, had just started coming into the country because I had just come <u>a few months</u>.</p> <p><b>Interviewer:</b> a few months, ok. and err at the time, how were you feeling?</p> <p><b>Asante:</b> (Pause) At the time, I had um <u>some serious problems</u>, um err I was having some <u>stomach ache</u> and some umm....what do you call them? some other um that comes under the arm pit and um here..</p> <p><b>Interviewer:</b> Lymph glands?</p> <p><b>Asante:</b> yes err lymph glands,</p> <p><b>Interviewer:</b> yeah</p> <p><b>Asante:</b> that's when I um became suspicious and um I went to the hospital</p> <p><b>Interviewer:</b> and um at that time, Asante, can you remember what your biggest worry was?</p> <p><b>Asante:</b> My <u>biggest worry</u> was how <u>would I tell the family</u>. My second biggest worry was <u>how am I going to survive?</u> err because <u>coming from Africa</u> knowing how people were dying and knowing how people wouldn't get any services or help to support them, then it was <u>a bit bad</u> for me. My feeling was this is <u>the end of the life</u>. This is the end of the life.</p> <p><b>Interviewer:</b> yeah, I can understand that this was really difficult...</p> <p><b>Asante:</b> it was, it was very difficult and stressful. I was on my own,</p> <p><b>Interviewer:</b> umm</p>	<p>Felt ill</p> <p>Sense of disorientation, <i>hesitation, something unexpected?</i></p> <p>Learned of being HIV positive in a foreign country</p> <p>Soon after coming into this country only here a few months</p> <p>Having stomach aches, swollen lymph glands</p> <p>Possibly symptoms of HIV? <i>maybe more difficult to talk about the emotional impact?</i> Talked about physical symptoms</p> <p>Thought he was dying, how was he going to tell his family?</p> <p>No services or support in Africa, did he think that it would be the same here?</p> <p>It's the end of the life</p> <p>Alone in a foreign country and thinking he is going to die, this is powerful, incomprehensible, frightening</p> <p>Plays this down maybe? 'difficult and stressful' 'a bit bad'</p>

<p>Sense of belonging diminished Translocation/displacement Persecution in Africa</p> <p>Regret about joining politics</p> <p>First time out of Africa</p> <p>Being helped</p> <p>HIV, the situation in UK- reluctance to access services Withdrawn/reluctant</p> <p>Empowerment Transformation New lease of life Forming of a self-identity that incorporates HIV HIV does not mean end of life</p> <p>Acknowledgement of the need for support and encouragement</p>	<p><b>Asante:</b> I had <u>left the whole family back in</u> [REDACTED] and um at that point in time I had been <u>arrested nine times in</u> [REDACTED] and during the arrest they would <u>inject us with blood and everything</u> and they would tell us <u>'we kill you with slow death or fast death.'</u> whatever we want to.</p> <p><b>Interviewer:</b> yeaah,</p> <p><b>Asante:</b> it was part of the <u>torture</u> and I was thinking <u>how am I going to tell the family? why did I join the politics of the country?</u> This is what led me to go into prison, because it was <u>T.B. infected</u> and everything was..it was a <u>bit bad in prison</u> and the <u>feeling was very very strong that I just saw the end of the life.</u></p> <p><b>Interviewer:</b> What was that like for you?</p> <p><b>Asante:</b> Err, um it was <u>lonely</u> being on <u>my own in err in a foreign land</u> and that being the first time getting out of my own country and err <u>not having lived away from the family including the extended family,</u> because <u>we do rely quite a lot on extended families</u> the whole <u>clan</u> itself, we rely on it and that made it very <u>hard</u> for me to <u>comprehend</u> to live that. It was organisations like this [REDACTED] that helped me a lot in this country that I started going on.</p> <p><b>Interviewer:</b> Ok, ok and at that time how were you told about organisations?</p> <p><b>Asante:</b> I was told about services in [REDACTED] and I was told about local services that I lived in</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> yes I was</p> <p><b>Interviewer:</b> How did you go about accessing them?</p> <p><b>Asante:</b> Um I had <u>some worries</u> you know, <u>facing some err other BME groups</u></p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> I <u>didn't</u> feel I could <u>trust them</u>, where as I could <u>trust</u> the <u>doctor</u> and the <u>nurses</u> better than <u>other organisations</u></p> <p><b>Interviewer:</b> yeah</p> <p><b>Asante:</b> coming from the <u>world that I lived in</u>, where there was no charitable societies because the economic situation had destroyed the welfare and charitable things and all these things . So it was hard for me to get to understand to go there, I'd relied on mostly, they said we can sign post you to these, I was very <u>withdrawn, reluctant</u> to do this.....other organisations that might be involved with other African or Black</p> <p><b>Interviewer:</b> And at that time where you able to speak to anybody about your experience?</p> <p><b>Asante:</b> yes I spoke to a [REDACTED] who brought me the air ticket to come over here, when I was arrested and I was on the [REDACTED]. So</p>	<p><i>Seems to flitter between talking about the HIV diagnosis and the persecution he experienced in Africa- are the two closely connected? both seem to signify the potential for death?</i></p> <p>Family concerns Survival End of my life Left whole family back home Politics Persecution 'We kill you with a slow death or fast death' Torture Why did I join the politics of this country? <i>Regret?</i> Disease, illness in prison <i>I wonder if the HIV diagnosis triggered a trauma response and made him think about the difficulties and the near death experience he had in Africa?</i> HIV organisations helped a lot <i>with diagnosis and displacement?</i></p> <p>Lonely First time out of home country Relied on extended family a lot 'clan' <i>Mixture of emotions</i> Hard to comprehend life without them (<i>because he thought he was going to die?</i>) HIV organisations</p> <p>Facing BME groups (<i>initial concerns about trusting BME groups?</i>)</p> <p><u>Did not</u> feel he could <u>trust</u> them (<i>BME groups?</i>) Trusted the doctors and nurses <i>Worlds apart?</i> No charitable organisations back home The economic situation was poor back home, destroyed charitable organisations <u>Withdrawn</u> and <u>reluctant</u> (<i>could they really help?</i>)</p> <p>Spoke to one person Who had brought him the air ticket to arrive in the UK</p>
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<p>Black African communities' response to HIV Stigma/gossip/rumours Isolation</p> <p>Confidentiality/sensitivity Empowerment</p> <p>Gossip/Stigma</p> <p>Renewed hope</p>	<p>a [REDACTED] for the [REDACTED]</p> <p><b>Interviewer:</b> right ok</p> <p><b>Asante:</b> He came here and [REDACTED] on the [REDACTED]</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> so the job paid him very good money because you are in the situation on the ground . Well one of the days I was, I, I <u>got arrested</u> by the <u>police</u>, I got <u>beaten and put in prison</u>. When I got out of prison he brought me an air ticket to come over so <u>he was my father, my mother, my brother he was my everything</u>. Even though I had only met him once in [REDACTED], he bought me the air ticket to come over here.</p> <p><b>Interviewer:</b> right ok</p> <p><b>Asante:</b> so he was <u>the very first person that I had to break the news</u> and [REDACTED] they like to get to the bottom of things, but he saw that I was not right so he <u>ignored it totally for quite a long time</u></p> <p><b>Interviewer:</b> yeah</p> <p><b>Asante:</b> until um, err, he was living with me in [REDACTED], in [REDACTED] at that time, he told me that he saw that I was a <u>bit uncomfortable</u> and then he started <u>talking to me</u> about <u>it</u>. Then err err after I was speaking to people [REDACTED] and so forth about it. About my experiences in prison, the experiences of being in the <u>haze of dictatorship</u> that want power above anything.</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> So breaking this <u>news</u> and <u>everything</u>, <u>empowered</u> me, <u>gave me the power to talk, to talk</u> to other people</p> <p><b>Interviewer:</b> yes yeah</p> <p><b>Asante:</b> to other people to start forming a [REDACTED], like the [REDACTED] that deal in partnership with other [REDACTED]</p> <p><b>Interviewer:</b> right ok... and what does having HIV mean to you now?</p> <p><b>Asante:</b> errr....to me err, i'm er it's <u>normal</u>, I'm <u>a normal person</u>, I <u>can live the same life that others live</u> and I can err I need it means that should <u>champion</u> again in the communities that I live in. That's what I think that being <u>HIV positive is not the end of the life</u></p> <p><b>Interviewer:</b> So what kind of things have changed now?</p> <p><b>Asante:</b> err, I err had, I, I, I, I, I'd <u>retired from life</u> on the <u>first day</u> that I <u>heard about it</u>. I'd retired from life, saying no no no no, this is the end of the life. Um but I feel I um...like <u>I am just like any other person</u> in the world who is <u>diabetic or who has got arthritis</u> who has got a disease as long as it is being managed.... I view myself as <u>an ordinary person</u>, as umm a person who still needs <u>support and encouragement</u> err, err a strong, a strong person and um I feel like I'm just like any</p>	<p>when Asante was arrested</p> <p>Beaten in prison Got out and he brought him the air ticket, even though he had only met him once <i>Saviour, someone who took him away, out of the violence, persecution. Bond like family, stronger than a family bond, good Samaritan</i></p> <p><i>He ignored 'it', like Asante was ignoring 'it' 'it'- being HIV?</i> <i>It's uncomfortable, not able to name HIV</i></p> <p>First person he broke the news to <i>about HIV?</i> <i>'it' the discomfort?</i></p> <p>Haze of dictatorship who want power above everything <i>Is HIV closely linked to the oppression, dictatorship, power imbalances, injustices the he experienced in Africa, treatment in prison?</i> Breaking the news, empowering (<i>loss of power, self potency, potential, permission to be oneself to empowerment</i>) to talk to other people Started forming support (<i>life line?</i>) <i>renewed hope, emergence of the forming of a new identity? from one that was uncomfortable to be with?</i></p> <p>I'm a normal person who can live the same life as others. Champion in the community (<i>purpose?</i>) HIV is not the end of life (<i>renewed hope</i>) Live a normal life I am like any other person who has diabetes, arthritis (<i>change in perspective</i>) <i>how long did this take?</i> I still need support and encouragement (<i>realistic</i>)</p>
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<p>Situation in the UK in relation to HIV Loneliness/Stigma Death of social self</p> <p>Emergence of a new sense of self with HIV Purpose</p> <p>Adjustment/lifestyle changes</p> <p>Reflection/attitude changes</p> <p>Acceptance Embracing others with HIV Meaning of life with HIV Purpose</p>	<p>other person or individual on the streets. <b>Interviewer:</b> And how do you think others view you? <b>Asante:</b> Others um, <u>my community</u>, it's got a very err <u>it does not welcome</u> many err <u>it does not welcome people who are HIV positive</u> They try to alienate them they do all this err, until now that <u>we talk about it</u>, we direct people to [REDACTED] we do partnerships with the [REDACTED] partnership and other organisations and other that's when the <u>community</u> is, because the <u>community is beginning....</u> they will <u>send some text messages</u>, oh 'don't talk to him', 'don't eat at his house', 'don't do this'. <u>That was what the community used to do.</u> And <u>now</u> what's happened obviously everything is just quite, whereas before people would <u>send text messages and all these things</u>, <u>it's just quite no one talks about it.</u> But we distribute condoms everywhere so what's the view of people have changed, but before it was 2009,10,11, oh it was horrible in [REDACTED]. In [REDACTED] I was <u>isolated</u> but there it was very multicultural you can get Indians and Black people, you can get white people with Blacks and mixed coloured [REDACTED] mixed Blacks... <b>Interviewer:</b> yes <b>Asante:</b> so it's a pity for <u>people that they do not understand</u> it was very <u>confidential</u> and <u>we tried to keep everything confidential</u> but <u>to give others a chance to meet with services.</u> So others they still have got um names, they still have got err <u>different perspectives</u>, <u>different views</u> <u>different thoughts on people who are HIV positive.</u> <b>Interviewer:</b> And err Asante I'm just wondering, leading on from that, when you first came to [REDACTED] what were your experiences of that? <b>Asante:</b> um when I came to [REDACTED] I didn't know many of the people and I went to the G.U. to pick up the tablets <b>Interviewer:</b> um um <b>Asante:</b> yes I did experience quite a lot because one as a [REDACTED] from [REDACTED], err <u>everybody knew me</u> but err getting to the G.U. itself, <u>walking into the G.U.</u> <b>Interviewer:</b> Yeah, yeah <b>Asante:</b> err, it was, it was like <u>people started saying</u> all these things but <u>not directly</u> because they <u>needed help from me legally</u>, and um they would go into court and give evidence and they did not suffer a lot <b>Interviewer:</b> yes <b>Asante:</b> there are <u>people</u>, but they <u>did not say anything specifically or directly</u> to me. Err there is <u>some difference</u> that I am with other people, because <u>people needed me</u> most than me needing them. <b>Interviewer:</b> What sort of a difference is there then between how you where feeling when you where first diagnosed with HIV than you how</p>	<p>Like any other person on the streets (<i>return to normality?</i>)<i>what's the definition of normal?</i></p> <p>Strong person-transformation- inner strength Survivor My community does not welcome people with HIV People try to alienate others We now direct people to organisations <i>What is the community beginning to do?</i> Within the community people would send text messages to others if they found out that someone had HIV. Things have changed now, it is quite, no one talks about it. (<i>HIV remains difficult to talk about</i>)people don't talk (<i>suppress, ignore?</i>, they stay quiet, however the gossip has stopped-signs of changes ? <i>Closed communities, excluding those with HIV</i> Asante is involved with HIV oraganisations, they distribute condoms Before, it was isolating and horrible <i>even in a mulitcultural setting?</i> It is very confidential and sensitive, but people need to be given a chance to meet with services</p> <p>People still have different perspectives, different views, different thoughts on people who are HIV positive (<i>is this related to stigma?</i>)</p> <p>Went to G.U. to pick up tablets Getting to the G.U itself, walking in (first time, frightening, stigmatising? not knowing what to expect?)</p> <p>People said things but not directly, they needed help, legally, (<i>Gossip, stigma</i>) People need me rather than me needing them (<i>position of autonomy, self sufficient</i>)<i>The realisation that others had more of a need for him, sense of value, purpose and thoughts of doing something meaningful with this,</i></p>
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<p>Raising awareness of HIV</p> <p>Change in attitude towards those with HIV</p> <p>Humiliation/torture/trauma/shame rape</p> <p>Forgiveness/compassion</p> <p>Victim of HIV</p> <p>Culpability Shame Embarrassment</p>	<p>you are feeling now?</p> <p><b>Asante:</b> Ow the <u>difference</u> is just <u>like the ocean an ocean</u>. I thought it was the <u>end of the life</u>. I thought um there's nothing that I can do with my life, there's no more life I believed this for <u>three years</u> or more.</p> <p><b>Interviewer:</b> And where did those beliefs stem from?</p> <p><b>Asante:</b> Um they all started from the country that I come from</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> um <u>our people</u> just <u>don't believe in medication</u> and they die so the thought is, it is not about the medication, <u>it is about when it attacks you, you just have to die.</u></p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> and you are <u>left alone to die</u> and <u>no one cares for you</u>. Unlike if you have a cut or something people rush you to the hospital , but when they know you are <u>HIV positive</u>, <u>they don't touch</u> you so and usually because of <u>malnutrition</u> and all these things, <u>in my country</u>, people could <u>die</u> of many <u>other things</u> if they are <u>HIV positive</u>. So for me that's where my beliefs came from. Because it gets you, you start feeling the symptoms and then you die. And people <u>just accept</u> this and that people <u>mustn't spread</u> the disease. So this is where I took it from because it's where I come from. It's what people talk about, '<u>he just got ill for two days and then he died</u>' and the post mortem is err pneumonia, it's HIV, pneumonia.</p> <p><b>Interviewer:</b> and Asante did you know anyone um back in [REDACTED] that who was diagnosed and then died in that way?</p> <p><b>Asante:</b> Yes I know <u>so many, thousands and thousands</u> of people who died that way in [REDACTED] because they didn't get medication and now they are still <u>dying</u> first maybe after two or three months my <u>first brother passed away</u> because <u>I could not get the medication</u> and <u>we did not get any help</u>. Yes I do know, I do know it's <u>very psychological</u> cos you now know that you are <u>going to die</u>. (Pause)</p> <p><b>Interviewer:</b> and err Asante, in what ways if any have you made any changes in your life following the diagnosis?</p> <p><b>Asante:</b> Changes in my life, I have made <u>so many changes</u> in my life err I try to <u>live very normal</u>, I err the diet, <u>I try to help other people in the community get over it</u>. I try to champion the err, the cause itself. I've changed a lot on um, on...I have feel about others and um <u>I have changed a lot</u> in my err, <u>my sexual life</u> as well. <u>I'm not very sexually active now</u></p> <p><b>Interviewer:</b> ok</p> <p><b>Asante:</b> it's a <u>secondary thing for me</u>. The <u>primary thing is to, to help others</u>, to give them, to <u>give them a lifeline</u></p> <p><b>Interviewer:</b> um, so so I'm picking up that there are two separate areas, one where your attitude towards others has changed</p>	<p>leadership?)</p> <p>The difference is like the ocean (<i>symbolic of the journey travelled, treacherous, turbulent, unknown, the sea has many lives contained within it, it has undercurrents</i>)</p> <p>I thought it was the end of life, that there is nothing I can do with my life.</p> <p>I thought this for three years or more (<i>what was life like for these three years?</i>)</p> <p>Our people just don't believe in medication, so when it attacks you, you just die</p> <p>You are left alone to die, when they know that you have HIV they don't touch you (<i>People with HIV become untouchable</i>)similar to the Hindu caste system, where those deemed to be a lower class are viewed as being untouchable)</p> <p>You start feeling the symptoms and then you die Where I come from, it is what people talk about</p> <p>Many, thousands of people die in this way, because they do not have medication, so people die after two, three months. My first brother passed away because I could not get medication. No help (<i>People die from HIV, a sense of helplessness about not being able to medication for first brother</i>)</p> <p>It is psychological because you now know that you are going to die (<i>death is imminent, not knowing when though, waiting to die</i>)</p> <p>Dietary changes, I help people in the community Sex life has changed, not very sexually active, it is not the primary thing. The primary thing is to help others, give them a life line (<i>Help others</i>) Idea about how people contract HIV, promiscuity, people look for it, his deeds (<i>Stigmatised ideas about who</i></p>
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<p>Masculinity Social constructions of masculinity</p>	<p><b>Asante:</b> yes <b>Interviewer:</b> So can you tell me a little bit more about that, in what ways? <b>Asante:</b> Um the <u>attitude towards others</u> is um <u>because I have been brought up in a country whereby the situation</u> is has to, has to do with the <u>idea that in order to get HIV men and women have to be promiscuous</u>, that person who has looked for it, his deeds and whatever thing <b>Interviewer:</b> um <b>Asante:</b> And err <u>it has changed a lot</u> into, into a <u>person who has</u> err <u>come to</u> err come to <u>to embrace</u>, to embrace others and to try to work with <u>them out of the situation</u> it is <u>not the end of the life</u>, like you like me when it's we need to let the world be HIV free but, to have it <b>Interviewer:</b> umm <b>Asante:</b> if its, if given the change would do, would do that. So my, I <u>embrace those people</u> who have <u>HIV</u>, I live with them, <u>I try and mix in the community with those who have and those who do not have it</u> so that they <u>understand each other better</u>. <b>Interviewer:</b> yes, yeah <b>Asante:</b> even though you <u>don't talk about it</u>, you know <u>condoms</u> and <u>these things</u>. I bring people to [REDACTED] to get their <u>HIV status checked</u> and all these things <b>Interviewer:</b> yes <b>Asante:</b> then people get professional help from qualified staff <b>Interviewer:</b> yeah so seeing it as something that <u>people themselves</u> are <u>responsible</u> for and almost yeah like you said <u>they sought it</u>, they seek it out <b>Asante:</b> yes <b>Interviewer:</b> and now from your own experience, you recognise that that's not always the case? <b>Asante:</b> It's not always the case err, it's not always the case I err, in my country that's where it comes from <b>Interviewer:</b> yeah that's where this attitude comes from? <b>Asante:</b> yes that attitude <b>Interviewer:</b> yes yeah <b>Asante:</b> yes and in um they also use the <u>same needles</u> in the hospitals and all these things <b>Interviewer:</b> umm <b>Asante:</b> And <u>some experience imprisonment</u> and the <u>life that we</u> or we <u>lived in prison, the rape that we went through</u> <b>Interviewer:</b> yes <b>Asante:</b> from other prisoners and so on. It <u>shamed us a lot, it shamed us a lot</u> and um yeah I do, I do see so many prison officers now</p>	<p><i>contracts HIV)</i> <i>(where these his thoughts prior to contracting HIV?)</i></p> <p>Come to embrace those with HIV, try to work with them It is not the end of the life <i>(acceptance of those with HIV)</i></p>
<p>Men are vulnerable too</p>	<p><b>Asante:</b> I try to mix in the community with people who are HIV positive, with those who have it and those who do not have it, so that they can understand each other better <i>(HIV as part of his self-identity?)</i> (a sense of belonging with others who are HIV positive?) Integration with HIV positive and non HIV individuals</p>	<p>I bring people to organisations to get their HIV status checked <i>('you' -people in the community?)</i></p>
<p>Shame/torture/rape</p>	<p>People are able to get professional help from qualified staff <i>(Giving others a chance to access support)</i></p>	<p>People are able to get professional help from qualified staff <i>(Giving others a chance to access support)</i></p>
<p>Religious beliefs</p>	<p>(HIV can be spread by other means in Africa, not only through sex, for example, used needles) <i>Blamelessness not everyone contracts HIV in the same way</i></p>	<p>(HIV can be spread by other means in Africa, not only through sex, for example, used needles) <i>Blamelessness not everyone contracts HIV in the same way</i></p>
<p>Forgiveness and compassion</p>	<p>Hospitals back home use same needles</p>	<p>Hospitals back home use same needles</p>
<p>Vulnerability of men Exclusion from services</p>	<p>Imprisonment, rape (unwanted sex) <i>Traumatic, shaming and difficult to talk about, male rape</i> Shame</p>	<p>Imprisonment, rape (unwanted sex) <i>Traumatic, shaming and difficult to talk about, male rape</i> Shame</p>





<p>Difficult to engage men-to bring them together</p> <p>Acknowledgement that men need support</p> <p>Praying helps-seeking sanctuary in prayer</p> <p>Church as a vehicle</p> <p>Support from organisations And family</p>	<p>itself has made it hard for men</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> hard, hard for men and if they ever that they <u>drink so</u> much than <u>women and then they get loose</u>, meet so many other women and they can't control themselves and this causes this spread of the disease, cos when you are drunk you might not think of the condom or anything.</p> <p><b>Interviewer:</b> Yeah</p> <p><b>Asante:</b> so because African women <u>do not usually drink or smoke</u>. But it is the <u>men who smoke and do drugs and all these things</u>. So men have just been <u>left behind</u>. If you see the prisons in this country, I can bet the percentage which is highest is for the men rather than the women so all this is in comparison to what I am talking about. I am talking about the state of not knowing their statuses</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> the <u>state of spread</u> and we are not getting enough support or <u>enough encouragement</u> because we do not have any organisation, so many women in [REDACTED], in this county rather than men's, rather than men's organisations so it's been <u>hard</u> to <u>penetrate</u> in them African men to penetrate or to get <u>African men together</u>, we try to do football</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> <u>to bring them together</u> and all these things, yes they do and we try to <u>meet</u> and <u>greet</u> and we try to talk to and share all these things so I think they are <u>forthcoming now</u>, we are <u>forthcoming</u> now us, us men rather than that iron fist that we used to have</p> <p><b>Interviewer:</b> so it sounds like now there's more um that there are more um more men sort of coming forward and saying they do need the support and that their does need to be support?</p> <p><b>Asante:</b> yes, yes er that's the situation now</p> <p><b>Interviewer:</b> yeah ok (pause) and Asante when you have difficult feelings or worries how do you tend to cope with them?</p> <p><b>Asante:</b> Ur if I've got <u>difi-difficult feelings</u> and <u>worries</u> I cope with them by praying. That's my first port, <u>praying</u> and <u>secondly going to other congregations</u> to meet other people and to talk to other people. Say you go to <u>watch football with others</u>, with <u>others</u> and then when I come back home I will be a bit relieved and start thinking afresh. I</p>	<p><i>Potential problems with not taking men's concerns into consideration</i></p> <p>There are big social problems that men have In the same way that African men do not know about their HIV status</p> <p>African men not getting enough support, encouragement or support Female orientated services (<i>men are marginalised</i>) Equally, It is difficult to reach men (<i>is this because services are well placed to meet the needs of men, in the way that they are set up for women</i>)?</p> <p>A way of getting men together through sports (<i>Building trust, bonds not talking about HIV directly?</i>)</p> <p>African men are more forthcoming now (<i>in his experience?</i>)</p> <p><i>Acknowledgement from men that they need support- what kind of support? what would this look like?</i></p> <p><i>Religion is important and significant in providing support</i> <i>Meeting others in congregations</i> <i>Gatherings- coming together- part of the ethnocentric Black culture? breaking the isolation</i> <i>Doing things in groups</i></p> <p>No drug, alcohol use Some men drink to forget or smoke to forget (<i>forget what, their HIV diagnosis? the social stigma surrounding diagnosis? a way to cope with the isolation and struggle of coming to terms with it?</i>)</p>
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<p>Father-child relationship my Son doesn't understand my situation</p> <p>Being a father is the best thing</p> <p>Missing the family</p> <p>Making connections in the UK with families and children But stopped after HIV diagnosis</p>	<p><u>don't drink beer I don't do drugs or smoke</u> err but my other friends they tend <u>to drink to forget or smoke to forget</u> which does not solve the problem <u>this is overriding the problem with a bigger problem</u>. For me I have um the <u>church as a vehicle</u>, where I meet other people and err pray for myself and my life. I visit um organisations that I work with or I talk to other people or just get onto the phone to talk to somebody who I trust</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> them that's <u>how I work out my way if I am stressed</u> or if I am in a situation that I cannot get out of. <u>I don't do it on my own because at the time I feel that I am a failure and might need someone's, someone's help. I might need someone's help.</u></p> <p><b>Interviewer:</b> and that support is there around you?</p> <p><b>Asante:</b> I do have a <u>very good relationship with organisations in [REDACTED]</u> and I do have <u>some support from the family itself</u>. The eldest is the problem <u>he's a boy or a man he thinks that everything has gone wrong because of me so he doesn't understand my situation</u>, he came from [REDACTED] when he was a bit old so he's still got that perception from [REDACTED]. So the others do not have any problem. So I do have support from family. I do have <u>support from friends</u>, from organisations and the charity itself.</p> <p><b>Interviewer:</b> yeah. Ok thank you. I'm just gonna move on now to talking about parenting and the first question is can you tell me about your experiences of being a father?</p> <p><b>Asante:</b> err <u>being a father</u> was the, in the beginning was <u>the best thing</u> ever, to become a father and err when I came into this country, I left the whole family back in [REDACTED]</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> I was very much isolated, I had no one to <u>talk to</u> that noise, I um use to <u>hear noise, children</u>, kids around giving me some problems, <u>pushing me around and all these things was not there</u>. And um err it <u>lowered my morale very much</u>, I created some other relationships with</p>	<p>Church as a vehicle- <i>transporting him through his life's journey? Enabling him to travel (to go through life with more ease?)</i></p> <p><i>Stress, unhelpful thinking makes him feel like a failure, is this because he has HIV? the way he contracted it?</i></p> <p>Good relationship with organisation and family? <i>belonging, sense of purpose?</i></p> <p>Concerns with older son- he doesn't understand A men he thinks, <i>able to make his own decisions?</i></p> <p>Perception of HIV from country of origin <i>What does he think about his father having HIV, that he will be isolated, a lone, no one will want to be around him? what if others find out?</i></p> <p>Has support from friend and organisations</p> <p>Being a father is the best (<i>fulfilling, rewarding</i>) Had left the whole family behind when coming to the UK</p> <p>Isolated</p> <p>Could hear children (<i>made him think about his family back home</i>) Lowered his morale <i>Connected with the black African community in the UK, made connections with families and spent time with their children- ethnocentric perspective, living within close knit communities and supporting each other.</i></p>
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Problems with bringing the family to the UK	<p>other <u>community members</u> so that I would build up some <u>connections with children in this country</u>, which I did, to <u>look after some other children</u>.</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> And then when I got to know about <u>my status I willed them to get out because I did not want them to know about the tablets</u> and about everything you know, <u>someone might not know</u>. So my children came from [REDACTED]</p> <p><b>Interviewer:</b> How long was it when um, before they came to the country from [REDACTED]?</p> <p><b>Asante:</b> Ow err I lived in this country for roughly 5 years before they came from [REDACTED]</p> <p><b>Interviewer:</b> ow right ok</p> <p><b>Asante:</b> yes five years because I needed to sort out my status and to get the um travel for them to come over and there were some few family problems it was never taking the children there were some other people back there because they know that when they are back there in [REDACTED] I would be sending <u>some money through to, towards their welfare in [REDACTED]</u>, so mainly <u>bringing them over, they would lose the family welfare as there were so many family problems. People were not helping me to get my children</u> because of that selfishness so it was a problem for me to <u>bring them over</u>. So when I brought them over there was this <u>very big problem</u> with their mother. <u>Their mother</u> was um...was now living with other people and got</p> <p><b>Interviewer:</b> and were they family members?</p> <p><b>Asante:</b> No, no other community, other members she was a <u>house girl</u></p> <p><b>Interviewer:</b> ahh...</p> <p><b>Asante:</b> they were <u>enslaving her</u></p> <p><b>Interviewer:</b> ahh right</p> <p><b>Asante:</b> on the basis of the family reunion, but she didn't know how she or that she can survive. So there were people being <u>enslaved</u> there in [REDACTED] and I had to involve the [REDACTED] to get my family. So parenting err was hard for me <u>because of the life</u> I had been pushed into. But I needed my family more because of my status and all these things. And to think or comprehend that I do not live with the</p>	<p>I willed them to get out, children and adults? <i>This community tie broke when he found out about his HIV diagnosis, in case people started asking questions about medication- others might find out</i>  <i>Adding to isolation, self-stigma, something is wrong and it's my problem now? Not able to tell anyone?</i></p> <p>Five years of not seeing his children  Problems getting his family to this country</p> <p>He had been sending money back home for his family  This money became significant for them back home, extended family, so they did not want this money to stop coming in. So things were made difficult for Asante, in terms of getting his family to the UK</p> <p>Wife was a house girl for one family in the UK and they had enslaved her. <i>Hardship struggle, not having permanent status in the country, open to exploitation (powerlessness, struggle)</i></p> <p><i>More determined to get family together, especially because of his HIV status, perhaps felt he needed them more, not knowing what he would be like in years to come, living with a long term health condition.</i>  <i>Realisation of his own mortality, the significance of being</i></p>
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<p>Children have a lot more rights to make their own choices in the UK</p> <p>Being HIV positive, I don't want my children to get into deep trouble</p> <p>Safeguarding children from problems- I would not want my child to end up same way</p> <p>Distance between my children and I</p>	<p><b>Interviewer:</b> yes, and because of the way you described losing the kind of the um, what's the word I'm looking for (pause) authority if you like</p> <p><b>Asante:</b> yes</p> <p><b>Interviewer:</b> I don't think that's the right word</p> <p><b>Asante:</b> yes that's the right word</p> <p><b>Interviewer:</b> yes in [REDACTED], there's that, that the <u>steal father</u></p> <p><b>Asante:</b> yes the iron fist</p> <p><b>Interviewer:</b> yes the iron fist that's rights...do as I say type thing</p> <p><b>Asante:</b> yes</p> <p><b>Interviewer:</b> And um what I don't know if this is correct, if I have got it right, I'm just checking with you, and when you came here the laws mean that some of that authority is almost undermined a little bit. I'm not sure if I have got you correct?</p> <p><b>Asante:</b> Yes, this is correct.</p> <p><b>Interviewer:</b> Ok, so what are the differences in the way you perhaps might communicate with the children or might have communicated with them in [REDACTED] to the way we do here?</p> <p><b>Asante:</b> Yes the communication <u>has changed a lot the way children have so much privacy</u>. Um they have got that um they have got that authority to say I'm sleeping out and all these things and um not to question them about that and <u>losing that grip as a HIV positive father I feel very bad for my children because they might end up in deep trouble</u> that's the power of the <u>government</u> of how if someone is HIV positive it's not easily visible so communication has changed. In the beginning err, I used to get the <u>mails, facebook</u>, their friends but now they've changed everything. They've got <u>new systems</u>, things that I don't even have so if they are communicating with a paedophile, I don't know. I don't even know. So um <u>communication</u> have <u>changed</u>, the respect, <u>they respect me</u> but they have got their powers vested on the laws of these lands,</p> <p><b>Interviewer:</b> yes</p> <p><b>Asante:</b> I can do this. So that err, that bridge, that <u>gap between me and my children</u> that worries me a lot, it worries me a lot, because not wanting to be very tough but my interests are to <u>safeguard my own children</u> from problems that they might face. <u>It's my priority. I wouldn't want my child to end up in the same state that I am in.</u></p> <p><b>Interviewer:</b> yes, yeah</p> <p><b>Asante:</b> and err, <u>even now they don't communicate, all the</u></p>	<p>western? adapting western beliefs and culture?</p> <p>Deculturation? 'Radical'-extreme- strong word to use- may be symbolic of the worries Asante had about his children and protecting them from harm?</p> <p>Bit by bit created a bond- <i>changed his style of parenting, became more authoritative in his parenting style, enabled him to bond with his children better, would this have happened in Africa?</i></p> <p><i>Has there been more opportunity for him to be more authoritarian in this country? Away from ruling with an 'iron fist'-away from a stern approach to parenting?</i></p> <p>Losing grip of children, as a HIV positive father <i>Children have the right, freedom to chose their actions, make choices. Is the right to guide them as a father lost now, because of the HIV diagnosis? Does this undermine his authority?</i></p> <p>Not wanting the children to end up in trouble Power of the government-legislation? differing <i>cultural norms on parenting in the UK?</i></p> <p>The gap between my children and I- worrying-nor knowing what his children are doing are they safe?</p>
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<p>Being HIV positive It means a lot to give my support to my children</p> <p>Rural communities in Africa are the most affected by HIV</p> <p>I will try to look after my children</p> <p>I wanted my children to quiz me about my medication, this is how I told them about HIV</p> <p>I Wanted them to know so that they could protect themselves from HIV</p>	<p><u>communication I get from them is over the phone</u> or they <u>can't even text me</u>. They all the <u>time text other people</u>, but they <u>can't even text me</u>, I'm <u>their dad</u> because <u>they don't even want to talk to me about anything maybe</u>. But <u>um meaning communication, um direct communication</u>, communication in the way they are living. Communication in um... in the current, current technology</p> <p><b>Interviewer:</b> yes yeah</p> <p><b>Asante:</b> It has all changed a lot for me</p> <p><b>Interviewer:</b> In what way has if any do you feel that being diagnosed with HIV has made a difference with being a father?</p> <p><b>Asante:</b> err, it has <u>not made a very big difference</u> to me, because I still <u>enjoy the same rights as a father</u>. I still err <u>see them as my children</u> and <u>they do not alienate me because I am HIV positive</u>. So I still have that authority, <u>even though the laws have taken a bit of the authority away</u></p> <p><b>Interviewer:</b> yeah</p> <p><b>Asante:</b> It's not my children, but it's the laws of the land that we need to abide by and do as <u>we must do</u> that's how I was taught when I lived in [REDACTED]. So it means a lot to me being a father and being HIV positive and giving my children support.</p> <p><b>Interviewer:</b> and have you any <u>thoughts in terms of their future</u> and your future?</p> <p><b>Asante:</b> My thoughts is to, my first thought is to go back to [REDACTED], my future is I believe in North, East, South, West, is always the best, always the best and um my future is in [REDACTED] and their future is, I can't see them going to [REDACTED]e and <u>being HIV positive</u> is working <u>with other organisations with people back</u> in my own country and trying to <u>find a way out of my situation</u>, because I know communities that are not reached by the government like in many <u>rural communities</u>. That's <u>farfetched information</u> to talk about, it's only important to talk about if someone dies then you see this <u>promiscuity</u>, because I have seen people at the <u>grave side saying it's like saying</u> 'I told him to leave those girlfriends' now look where he is and that's what, what it takes, but I need it, um...life, <u>I'm alive and I will go as long as I still have</u> life</p> <p><b>Interviewer:</b> Umm</p> <p><b>Asante:</b> and I <u>will try and look after my children</u> and till the time they</p>	<p>Technology- 'new systems' changes in technology means that children could be unsafe online and from HIV?- 'same state that I'm in'</p> <p>Little communication between them. Don't text or call They don't want to talk to me <i>A sign that his children are more independent now?</i></p> <p>Being HIV positive hasn't changed the relationship with his children, still has the same rights</p> <p>However cultural norms and legal rights have taken some authority away Still has authority- <i>although one son, does not communicate with him much, the others speak to him less frequently too. Is this a sign of their independence, or not wanting to be too close to their father because that bond has not been broken or not established well from the onset?</i></p> <p><i>Law of the land, not the children (could cultural differences in parenting be a way of explaining a fragmented or not very close relationship with his children? Although it is very clear that he cares a lot for them, and wants to be more a part of their life</i></p> <p>Being a father and being HIV positive, mean giving them support</p>
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<p>HIV wasn't my fault</p> <p>One son had seen the devastation in Africa, so he didn't respond well to the news</p> <p>Son is away from home</p>	<p>will themselves away. <u>I will walk with them until they will themselves away from me</u>, and I will do some work in Southern Africa with doctors and nurses and others to see so that they can work together</p> <p><b>Interviewer:</b> How did you, you make your children aware of the diagnosis?</p> <p><b>Asante:</b> I spoke to them one by one and err um they...<u>I needed some tables so as a father I asked them can you give me those tablets? and I wanted them to quiz what tablets I am taking</u></p> <p><b>Interviewer:</b> um</p> <p><b>Asante:</b> and all these things and for them to, to, to know about it because I needed to give them a <u>life line again</u> to watch out that there's this in the world but stay away, <u>use protective equipment</u> or if, possible, whenever it is possible so I talked to <u>them directly</u> and err one by one and they err understood it</p> <p><b>Interviewer:</b> Ok, and how do you currently feel about the decision you made to share your status with your children?</p> <p>I <u>feel great</u> because <u>they still respect me</u>. I feel that they can be cautious about their life whenever they go out and err, they again are taking the decision. It was <u>very hard for me</u>, but, it was not my fault, I had only one wife</p> <p><b>Interviewer:</b> yes</p> <p><b>Asante:</b> It's not their mother's fault it was because I was encroaching on this other territory that I went into the <u>political problem</u>.</p> <p><b>Interviewer:</b> yeah</p> <p><b>Asante:</b> and err they are great</p> <p><b>Interviewer:</b> yeah, yeah, that's another question I was going to ask you, how did they respond when you told them?</p> <p><b>Asante:</b> they didn't have any problem, maybe it was because of their age at that time. But the elder <u>one did not respond very well</u>.</p> <p><b>Interviewer:</b> How old was the older one at that time?</p> <p><b>Asante:</b> He was 16, he was 16,</p> <p><b>Interviewer:</b> so how did he respond?</p> <p><b>Asante:</b> err, he had just come in from [REDACTED] and had experienced all these things in [REDACTED] and <u>how HIV and Aids are bundled together</u> and so his <u>reaction was 'what can I do, you are my father?'</u> But, there was a but it means that he had <u>so much reservations</u></p> <p><b>Interviewer:</b> um, so it almost sounds like he was um, he was torn</p>	<p>The future- would like to go back to Africa and support rural communities there, working with medical staff to raise awareness of HIV</p> <p><i>Will support his children, until a time when they will themselves away- become less dependent on him?</i></p> <p>HIV disclosure- told his children one by one</p> <p>By requesting that they bring him his medication, so that they can ask him about it</p> <p>He wanted them to know about HIV do that they could protect themselves from it A lifeline- source of support, advice and guidance- to protect hem</p> <p>Children continue to respect him, they can be more cautious in their lives and make different decisions</p> <p><i>Victim of HIV through his involvement in politics and the persecution he faced in prison</i></p>
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<p>He turned to religion for support, but is away from the family</p> <p>Families should not play blame games</p>	<p>between having all these ideas and understanding of what HIV is in [REDACTED]?</p> <p><b>Asante:</b> yes</p> <p><b>Interviewer:</b> and then thinking about it in terms of you having it and not necessarily understanding what this means here?</p> <p><b>Asante:</b> yes</p> <p><b>Interviewer:</b> this was possibly confusing for him?</p> <p><b>Asante:</b> yes it was all confusing because <u>like me coming from [REDACTED]</u>, knowing how people were <u>dying</u> and all these things it was <u>very hard</u></p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> it was very hard</p> <p><b>Interviewer:</b> and your oldest son had seen all that I guess, cos he was old enough to understand</p> <p><b>Asante:</b> yes</p> <p><b>Interviewer:</b> so yeah How long did it take do you think for him to gain a more <u>balanced perspective</u> and more of a <u>realistic idea</u> of what it is like to have HIV in this country?</p> <p><b>Asante:</b> <u>I don't know</u> he keeps himself to himself and he has joined the [REDACTED]. They are <u>very strict</u>, they are <u>very strict</u>, and you tend to lose your children again to them because they can be [REDACTED] and go out everywhere. So yeah he understood, and <u>he embraced me as a father, but he had some reservations. The medication and all these things</u>, he didn't have any problem he err accepted it and I told him everything</p> <p><b>Interviewer:</b> I'm just interested Asante, you say he joined the [REDACTED] yeah, did he join that organisation?</p> <p><b>Asante:</b> yeah he joined yeah</p> <p><b>Interviewer:</b> and how did you feel about that?</p> <p><b>Asante:</b> I don't know what this organisation and the people are. They keep themselves to themselves</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> They talk about God but I don't trust the church itself. I don't even understand where they come from and where they are going. So I was a bit worried about him being a member of that, being a member of the [REDACTED] and because I didn't know about it. I know about</p>	<p>Older child did not respond well, he was 16 at that time and he had seen what life was like for people in Africa who had HIV HIV and Aids bundled together-</p> <p>Doesn't communicate a lot with Asante</p> <p>People dying</p> <p>Older son went away from home, joined a religious group, Asante describes them as being very strict <i>Need for order, rules for living, discipline maybe? When things are difficult to understand/comprehend</i></p>
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<p>Family fragmentation leads to isolation</p> <p>It's important to speak up about HIV so that family can get support</p> <p>Families need to stick together</p> <p>It's important for people to know their status</p>	<p>Christianity, Judaism, I know about Islam, but not about [REDACTED]</p> <p><b>Interviewer:</b> umm</p> <p><b>Asante:</b> So it was a <u>bit worrying</u> for me but I can live with it was a long as he's not drinking, he's not doing anything that is bad.</p> <p><b>Interviewer:</b> I'm just coming to the end of the interview now Asante, so</p> <p>I'm just wondering if there's any knowledge or information that you want people to know or pass on about HIV. What would that be? In particular what would you say to children and their parents who are HIV infected or affected?</p> <p>Asante: I would want them to know firstly is that it is not the end of the life. And <u>families should not play the blame games</u> but they should find the <u>best way forward</u>. If someone gets into such a situation and support them morally, financially, emotionally and physically. This is what I would want families to be to be together to help save and accept that life. I believe in charity begins at home rather than getting out there and publicising and doing all this other work. <u>Motivating the family to do all these things is very important. because if it gets into the family and the family does not know where and how to get support or what to do, err where to go where to get condoms and so forth. It's the elimination of an individual every year, every day. Because you might not know about that person's status, you might not know where to get the treatment, where to get support, where to get support from organisations and all these things so my advice is that people should come out and tell others. People should learn to embrace those who have it. People should live normally so that people are not sidelined, it's a matter of loving each other, supporting each other and believing in each other. And whatever the medical staff, the doctors, the consultants, those people will not be there every day. But the family, they will be there every day of my life so they are the best people to deal with my situation</u> to deal with medication and all these things. It's the family that helps to remind me to take my medication, especially if I'm stressed and everything, I could forget to take my tablets. So <u>family are very important support</u>. Second are the doctors and nurses. Family support can also made the doctor's job easy too. As it is <u>important to take medication regularly</u>.</p>	<p>A bit worried about his son.</p> <p>But he's not drinking, he's not doing anything bad <i>Asante thinks that his son is safe and well and this is reassuring for him</i></p> <p>Families should not play the blame game. Is this something that tears families apart?</p> <p>Need for greater support Family members helping each other,</p> <p>Helping families to seek support</p> <p>Promoting information about treatment and support for HIV- <i>combating stigma?</i></p> <p>People are sidelined <i>treated like they don't exist-outcaste?</i></p> <p>However families are there every day, To support and care <i>Carer support required?</i></p>
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<p>My son's response to me having HIV has motivated me to work with communities, extend my family</p>	<p><b>Interviewer:</b> yes that makes sense, it makes sense. Cos that's essentially the support system</p> <p><b>Asante:</b> yes</p> <p><b>Interviewer:</b> the primary support system</p> <p><b>Asante:</b> yes the primary they get the chance to say, hey take your tablets its eight o' clock. You need to take your tablets and this is what is needed, people <u>who care surrounding them</u>.</p> <p><b>Interviewer:</b> What would you have liked to know about your diagnosis back then, that you know now?</p> <p><b>Asante:</b> What I have learnt is that you need <u>to live your life to the fullest</u>, that there is no going back, by getting the treatment, by getting tested and not to <u>live on the periphery</u>, not knowing your status and <u>playing hide and seek with the doctors</u> and nurses because you can't afford not to know your status. It's all of these things that I have learnt that you need to live by it cos' it's the reality</p> <p>██████████: and is there anything else to wrap up the interview that you would like to add about your experiences of living as a father with HIV.</p> <p><b>Asante:</b> <u>living as a father having HIV has</u> err, has changed my life the most because <u>it has taken one of my children away from me</u>. Not very far, he's still close to me, but not that close and secondly it has made me have a <u>bigger family and a bigger community</u> as well, that I didn't have if I had not ██████████ and started working with them.</p> <p><b>Interviewer:</b> So I get the sense that you are not just a father to your biological children, you are a father to the children of the community as well, who may be affected or even infected with HIV</p> <p><b>Asante:</b> Yes those who are living with it, yes I am a father to both of those. I'm going there now and err they are waiting for me there. There can be 40 -50 people there, just saying hello to them, they can feel very much comforted. Just a minute with them is good enough for them.</p> <p><b>Interviewer:</b> thank you, thank you</p>	<p><i>Essential support system- many live away from their families though?</i></p> <p><i>Getting tested is important- change in attitude Transformation, more comfortable with diagnosis and talking about it</i></p> <p><i>Can see the benefits of talking about HIV, helping others to realise that there is life after diagnosis</i></p> <p><i>Here HIV is the reason why children have become more distant from him. Previously it was the change in cultural practices of parenting and children having rights in this country- a contradiction- a difficulties grappling with a fractured relationship with children maybe? The distance, what caused this, cultural changes, immigration? being away from children for 5 years? them going up and becoming more independent, seeking autonomy, integrating into western culture, or the HIV diagnosis, loss of authority, respect because of the way that it is commonly transmitted, the stigma surrounding it, bringing with it, its social problems,</i></p> <p><i>The fact that Asante is heavily involved with HIV organisations- does this cause issues for his children?</i></p> <p><i>Asante has drawn closer to the wider community, with others infected or affected by HIV, is this where he now feels more comfortable? around those with the same diagnosis- a sense of belonging of knowing who he is again?</i></p> <p><i>Away from those who are not HIV positive, do they truly understand? Do they really want to understand? or do they just want to distance themselves from it? including his children?</i></p> <p><i>Does Asante know? is he struggling to articulate this? or is it that he does not want to say because it is too difficult? has he thought about it before?</i></p> <p><i>Asante goes back to talking about his involvement with HIV organisations and what he does for people accessing services. He identity in the community is stronger, this is clearly where he feels the most comfortable.</i></p>
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## Appendix J - Annotated worked example of a theme

### *Physical symptoms of AIDS*

Uncontrollable physical changes

Fear of the unknown

Shocking news

Questioning survival

Death of physical self

### *Separation/disconnection from family*

Isolation

Loss of social self

Missing family

No support

### *Trauma*

Persecution in Africa

Shaming experiences

Fleeing political unrest

Ideographic themes

### *HIV means end of life*

Death penalty

There's no more life

### *HIV in Africa*

Left to die

Culpability

HIV doesn't exist

### Sublimation

These two subthemes

formed the basis of

master theme-*the*

*demise of the physical*

*and social self-this*

draws other related

themes together

## Appendix K - Present and absent themes for participants

Themes							Present in over half the sample?
	Asante	George	Bongani	Mehtab	Dayo	Ekua	
symptoms of AIDS "It means death, like a death penalty"	Yes	Yes	Yes	Yes	Yes	Yes	Yes
"In Africa you are left to die"	Yes	Yes	Yes	Yes	Yes	Yes	Yes
"I had nobody"	Yes	Yes	Yes	Yes	No	Yes	Yes
"It's not safe to talk"	Yes	Yes	Yes	Yes	Yes	Yes	Yes
"Accessing treatment and support isn't easy"	Yes	Yes	Yes	Yes	Yes	Yes	Yes
"You tell them that you are HIV positive and you have built a wall around you"	No	No	Yes	Yes	No	Yes	No
Breaking the silence	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Intimacy is difficult-challenging the mythical stereotype	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Drawing support from the church	Yes	Yes	Yes	No	No	No	No
Paternal HIV disclosure	Yes	Yes	Yes	Yes	Yes	Yes	Yes
A Father's loss of authority	Yes	No	Yes	Yes	Yes	Yes	Yes

## **Appendix L- A reflexive account of the research process**

### **1. Development of the research question**

Prior to commencing the doctorate programme, my research experience related to these areas; the over representation of black and ethnic minorities with in mental health systems; health and illness; the marginalisation of victims in the criminal justice system and the experiences of older single South Asian women. In relation to my work experience, I had worked in the area of adult education, domestic violence, substance misuse, forensic, custodial settings and primary care. Through this work experience and learning about physical health conditions both as an undergraduate as well as a post graduate student, I had become increasingly aware of the association between physical and mental health and the impact of long term health conditions on psychological health. My interest in this area had been further heightened when I gained employment within an NHS Improving Access to Psychological Therapies (IAPT). Here I was increasingly delivering psychological therapies to people who had long term health conditions, and became interested in the areas of diabetes and chronic pain.

On embarking on the doctorate, I wished to further my understanding and knowledge of long term health conditions and therefore gained a placement in a Clinical Psychology, Medical Health Department. Here I had the opportunity to learn about HIV. As part of my role as a trainee counselling psychologist I took referrals from the Genito-urinary department, for people with a new diagnosis of HIV and I grew more aware of the struggles that people diagnosed with HIV experience, their concerns of stigma, discrimination, trauma and often hyper vigilance about changes in their body or symptoms. What I was struck by the most was the structured, medical environment people are frequently asked to visit for routine check-ups, I worked predominantly with gay men and members of the black African community. One thing I began to notice and experience frequently was the rates of missed appointments amongst black African men. I had a number of opportunities to work with black African women and they frequently had conversations with me about their children, their struggles, challenges and worries about disclosing their HIV status to their children, in cases where this had not happened, but men's voices were silent, unheard, and this raised my curiosity as to why this was the case. Here black African

fathers living with HIV was the subject that seemed under researched and effectively silenced.

Therefore in the early stages of the development of the research question, I approached HIV charities and discussed ideas with organisation leads and looked at previous research that had been carried out in this area. I decided that I wanted to explore the lived experiences of black African HIV positive fathers residing in the United Kingdom. This research idea was received well both by the university and HIV charities. The charities also reported research in this area of black African fathers living with HIV is limited. Again this helped me to gain recognition of their silence and invisibility within services and indeed research. I was therefore concerned that I may not get the required participants for this research, given that they are a hard to reach group. However I had formed good working relationships with organisations who reassured me that they would do everything that they could to support the research and indeed they remained true to their word.

## **2. My suitability as a researcher**

At this point I also reflected on the fact that I am a South Asian female conducting this research and wondered whether men would want to talk to me about their experiences. I was beginning to understand the heterogeneous aspects of African culture, through my involvement with black Africans with a new diagnosis of HIV. Therefore my doubts about my ability to carry this research project become prominent. I began thinking about this in the context of my clinical practice and thought about the times when meeting a client for the first time, I do my best to understand their own idiosyncratic world view. I have to think about the assumptions I am making and tentatively explore these with clients if and when appropriate. Through talking, hypothesising and testing these hypotheses collaboratively, I get a better understanding of the challenges and concerns that people are facing. This also made me reflect on the philosophy of counselling psychology, with its emphasis on pluralist practice and engagement with subjective and intersubjective values and beliefs. My anxieties were put at bay slightly by the knowledge and awareness that the participants choosing to be interviewed would be the experts of their cultural experiences, and I would become familiar with this through the research process. I

needed to maintain a stance of curiosity, respect and non-judgement to be able to complete this project effectively and ethically.

Given my adopted stance on this subject, I was curious about observing myself when I came in to contact with this group of people and the kind of prior assumptions I had in fact picked up. These thoughts validated the importance of reflecting on the research process as it unfurls and keeping a reflective diary throughout the project. I was also curious to find out why black African fathers have in some cases been absent from their families. The literature I was beginning to read was also highlighting this.

As I developed my research questions I thought carefully about keeping them open and broad so that participants could tell me about their experiences and the things that were important to them. I developed a poster to distribute to HIV charities and I soon received interest in my research and men were willing to participate.

Through the process of carrying out the interviews, I was struck by the resilience of these men, their stories of loss, abuse, love, hope and appreciation for life was moving. Each person that I interviewed had their unique experiences and understanding of their lived experience. Each was grateful to be alive after having lost so much. The prominent aspects of their narratives were about their wish for a different future for their children regardless of whether their children were living with them or away from them. Each wanted to ensure that their children did not contract HIV. The men talked about the cultural differences of raising children in the UK to Africa and the clashes that they experience with their children; the way in which their relationship with their children has changed since their diagnosis of HIV. It was difficult to decipher whether their feeling of a loss of authority and powerlessness had resulted from their migration to this country and changes in cultural practices of fatherhood, their children growing up and requiring more autonomy, or whether their loss of authority had resulted from the HIV status. All of these variables in some way were impacting on these men and their thoughts about their relationship with their children, all men had made efforts to stay connected with their children. I began recognising that being fathers was an important role and one that men did not take lightly. This served to challenge dominant discourse about absent black African fathers.



As I read about the historical context of fatherhood in Africa, I began to understand the part that colonialism, apartheid and capitalism had played in separating men from their families. I also came to understand the concept of hegemonic masculinity and the impact of cultural norms and expectations in relation to having multiple partners; the ways in which this increases their risk of contracting HIV. The participants in this study spoke openly to me about the ways in which their HIV status directly impacted on their intimate relationships and the adjustments they had to make. Increasingly, I became aware that the men had to make significant changes to their lifestyles and work towards integrating their HIV diagnosis into their identities. as their HIV status permeated through every aspect of their lives.

The self-stigma they experienced was evident throughout the interviews and their reluctance to talk about their HIV diagnosis within their community. This made me realise that the men were experiencing challenges associated with migrating to a different country, becoming accustomed to a new way of life, some had left their families behind, so their isolation was great and in addition to this, they had been diagnosed with HIV, which added to their isolation. Some spoke to me about the atrocities they had experienced in their country of origin, in relation to the political persecution and violence. These stories were moving and at times difficult to listen to. I was astounded at the positivity these men had and their enthusiasm for life, which was inspirational. At the same time, my thoughts were focussed on the multiple, compounding factors the men have negotiated and worked through to be where they are today. This began to give me some understanding of the challenges and difficulties men have with seeking support for their HIV diagnosis, given the challenges to their identities.

I noticed that that stigma was a strong theme in this research, although no direct questions had been asked relating to this. The interviews were an opportunity for participants to talk about the things that they wished to, and their experiences of stigma was a strong theme. I wonder whether my own experiences of stigma and difference may have influenced my interpretation and analysis of data, although every effort was made to ensure the trustworthiness and transferability of the research findings (see appendix M).

## **Appendix M - Trustworthiness and transferability criteria**

### **Credibility.**

#### *The adoption of research methods that are well established*

This research adapted the IPA and followed the guidelines of carrying out an IPA study as outlined in Smith, Flowers & Larkin, (2009).

#### *The development of an early familiarity with the culture of participating organisations*

The researcher attended the charities that took an interest in this study, met with managers and talked to them about the study, she also familiarised herself with the services delivered, once ethical approval of the study had been gained.

#### *Random Sampling*

To ensure homogeneity of the sample, a purposive sample was acquired, however those wishing to take part in the study, following their initial triage with the managers of the services to ensure their suitability, were given the opportunity to be interviewed.

#### *Triangulation*

Semi-structured interview questions were utilised which enabled participants to talk about experiences pertinent to them, this was also important in maintaining an idiographic focus of IPA. The researcher ensured that all themes identified in this study were grounded and validated by direct quotations from participants.

#### *Tactics to help ensure honesty in informants*

Participants were informed that the researcher was independent of the charities so that there were no conflicts of interest, they were assured that there were no right or wrong answers and that they had the time and space to talk about aspects of their experiences that they wished to. Respect was given to those who chose not to elaborate on answers further, they were also informed of their right not to answer questions. All these procedures were not only implemented to ensure that no harm would occur to participants during the interview process, but to also make certain that participants felt comfortable to be honest about their experiences.

#### *Iterative questioning*

The researcher employed this when it was felt appropriate, especially to make certain that she had understood the meaning of the points that participants were making. However this was not employed when participants spoke about particularly sensitive subjects that had the potential to cause further distress if iterative questioning had been employed.

#### *Negative case analysis*

The researcher went back into the data to check that the themes were grounded in the quotes for each participant.

#### *Frequent debrief sessions*

Frequent meetings with supervisors took place to confirm that themes and analysis were fitting to quotes and any flaws were highlighted.

#### *Peer scrutiny of research project*

Oral presentations of the research took place on numerous occasions with peers and academics through the annual progress review and poster presentations both at the University of Wolverhampton and the Division of Counselling Psychology Conference 2014.

#### *The researcher's reflective commentary*

The researcher kept a reflective journal throughout the research process (see critical appraisal).

#### *Background, qualifications and experience of the investigator*

The researcher has carried out qualitative research at an undergraduate and post graduate level, all of which involved interviewing participants

#### *Member checks*

participants were not asked to check transcripts for accuracy as this is against the IPA concept of co-creation of data, this was reinforced by Dr Gil-Rodriguez and Dr Hefferon (2013).

#### *Thick description of the phenomena under scrutiny*

This is contained in the literature review.

#### *Examination of previous research findings*

Contained in the literature review.

### **Transferability.**

Qualitative studies, such as this IPA research study utilised a small sample of six participants therefore it is impossible to demonstrate that the findings and conclusions are applicable to other situations and populations (Shenton, 2004).

Nonetheless theoretical transferability is achievable and this has been demonstrated in this study through idiographic accounts, through thick descriptions of experiences of living with HIV and how this impacts on black African men's roles as fathers.

Participants were recruited from two HIV charities and six participants were recruited all together. Six separate interviews took place between February-June 2014. The interviews lasted between 40-60 minutes (Please see appendix G for the exact length of each interview).

**Dependability.**

The process undertaken to ensure dependability of research can be seen in earlier sections of this chapter that detail clearly the procedure undertaken by the researcher in conducting this study to ensure that this study can be replicated, (please also see the critical appraisal). However it should be noted that repeating this study may not gain the same results, this is because the phenomena under investigation is not static, however this study and its findings are static and depict the present, therefore the study can be useful in informing future studies, if not necessarily to gain the same results (Shenton 2004).

**Confirmability.**

Findings reported in this study have derived as a result of the experiences of the participants rather than the researcher and this was further made certain by checking that the themes related to the transcript quotes through consultation with supervisors to verify that the themes arrived at were appropriate.

## **GLOSSARY**

**AIDS-** Acquired Immunodeficiency Syndrome

**BME-** Black and Ethnic Minorities

**BPS-** British Psychological Society

**HAART-** Highly Active Antiretroviral Treatment

**HCPC-** Health Care Professionals Council

**HIV-** Human Immunodeficiency Virus

**IPA-** Interpretative Phenomenological Analysis

**IRM-** Illness Representation Models

**NAT-** National AIDS Trust

**NICE-** National Institute of Clinical Excellence

**PLHIV-** People Living with HIV

**PTSD-** Post Traumatic Stress Disorder

**WHO-** World Health Organisation